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Assessment and tools for follow up of patients' recovery after intensive care

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SCHOOL OF
HEALTH SCIENCES
JÖNKÖPING UNIVERSITY

DISSERTATION SERIES NO. 30, 2012

JÖNKÖPING 2012

Publisher: School of Health Sciences
Print: Ineko AB

ISSN 1654-3602
ISBN 978-91-85835-29-4

"I am always willing to learn,
however I do not always like to be taught"

Sir Winston Churchill

Abstract

Aim: The overall aim of this thesis was to describe and explore the use and content of ICU-diaries and to develop and psychometrically test a questionnaire to detect physical and psychosocial problems for ICU patients in their recovery process.

Methods: This thesis is based on four studies. Study I had an explorative descriptive design with a quantitative and qualitative approach. Data were collected by telephone interviews with staff at Swedish ICUs (n = 65) which kept ICU-diaries. One question "what was the purpose of keeping ICU-diaries" was analysed with latent content analysis, and the other data were analysed with descriptive and comparative statistics. Study II had an explorative descriptive cohort design with a concurrent mixed method approach. The sample in study II was a part of the sample in study IV in which 421 former ICU patients responded to a new developed questionnaire 3-set 4P two months after discharge from ICU. Patients from this sample who have had an ICU-diary (n = 115) responded to a questionnaire six months after discharge from ICU. Fifteen patients were interviewed about the content and usefulness of the ICU-diary. Data were analysed with descriptive statistics, descriptively by content and interviews with manifest content analysis and then combined at the interpretive level to seek convergence, as enable by the mixed method approach. Study III had a methodological design. In this study, the questionnaire 3-set 4P was developed and psychometrically tested in a pilot setting. In study IV, the questionnaire was further developed and tested based on psychometric evaluation of the 3-set 4P. In study III the questionnaire was responded by 39 patients and in study IV by 421 patients. Data in study III and IV were analysed with descriptive statistics and psychometrical tests.

Results: The main purpose for keeping ICU-diaries was to provide a tool in the recovery by helping the patient remember and give time back. Keeping ICU-diaries was common although there was a difference in practice and patient recruitment among different hospitals (study I). An ICU-diary with content and photos in a chronological order describing the whole picture of critical illness and ICU stay could be a tool for the patient to construct a coherent individual story. The ICU-diary could be one piece to give a deeper

understanding and meaning in the personal story and to give a realistic expectation of the recovery process. Absence of guidelines for keeping ICU-diaries could affect the possibility for the ICU-diary to be a helpful tool during the recovery process (study II). In study III, the 3-set 4P was developed to be used for identifying and evaluating former ICU patients' physical, psychosocial problems and outcome during follow-up. The psychometrical tests showed acceptable validity and internal consistency reliability. The stability reliability was acceptable in two of three sets. The psychometrical tests of the further modified version of 3-set 4P in study IV showed good construct validity and internal consistency but it needs some modification before it can be used in clinical practice (study IV).

Conclusion: Recovery can be a difficult process where different tools can be useful. Today there is no evidence about tools to use during follow-up. To promote high quality of the follow-up there is a need for evidence-based guidelines. The ICU-diary is one tool but this thesis shows that guidelines for keeping ICU-diaries have to be developed to meet the patients' wishes in order for the ICU-diary to become a useful tool during the process to recovery. The 3-set 4P can after some modification be used at the follow-up clinic to identify the individual patient's problems and create an individual program for recovery.

Original papers

This thesis is based on the following papers, which are referred to by their roman numerals in the text:

Paper I

Åkerman E, Granberg-Axéll A, Ersson A, Fridlund B, Bergbom I (2010). Use and practice of patient diaries in Swedish Intensive care units: a national survey. *Nursing in Critical Care,* 15 (1) 26-33.

Paper II

Åkerman E, Ersson A, Fridlund B, Samuelson K (2012). Preferred content and usefulness of an ICU-diary as described by ICU-patients a mixed method analysis. Accepted in *Australian Critical Care*.

Paper III

Åkerman E, Fridlund B, Ersson A, Granberg-Axéll A (2009). Development of 3-set 4P questionnaire for evaluating former ICU patients' physical and psychosocial problems over time: A pilot study. *Intensive and Critical Care Nursing,* 25 (2) 80-89.

Paper IV

Åkerman E, Fridlund B, Samuelson K, Baigi A, Ersson A (2012). Psychometric evaluation of 3-set 4P questionnaire. Resubmitted to *Intensive and Critical Care Nursing.*

Contents

Acknowledgements

Research is a process starting with the curiosity to acquire more knowledge. This thesis has given me knowledge about tools to be used as a help in the critically ill patients' process to recovery. Therefore, the most important persons to thank are the patients. Former critically ill patients are usually physically weak and mentally distressed, nevertheless, they have taken their time and efforts to respond to questionnaires and taken part in interviews. Hopefully, this has given valuable experience to both parties. The next step is to use the knowledge from this thesis to develop a qualitative follow-up for the patients.

Many people have been there and supported me during the PhD studies and I want to express my thanks to all.

My tutor Bengt Fridlund who has supported me and always been there listening to the good and the bad news. With a never ending patience he has given me good advice, and with his deep knowledge, making me think one step further, I have gained new insight into the problems. I am going to miss our inspiring discussions.

My co-supervisor Karin Samuelson for constructive discussions and comments which have helped me increase the quality of the work.

Anders Ersson, my co-supervisor and my boss at the intensive care department; thanks for encouraging and inspiring discussions. Your open mind and ideas have lifted the work to higher dimensions.

Thanks to my student colleagues and friends both at Jönköping University and in all the courses, thank you for constructive discussions and for providing an inspiring and positive environment.

Ingegerd Bergbom and Anetth Granberg-Axèll, co-authors, thanks for being a part of the work.

Carina Fredriksson, thanks for the help with the linguistic revisions both of the articles and of the thesis.

Amir Baigi, the statistician for never losing patience with all my questions.

My lovely children Andréa and Oliver, hopefully I will have more free time now and you will not have a mother deeply consumed by books, studies and the computer.

I also want to thank the Skane University Hospital, Department of Intensive Care Medicine in Malmö for the professional support that made this thesis possible.

Introduction

"To the intensive care unit you come to live, not to die. We give you a chance to hang on to life, to restart and to survive – that is what we do.
Then, when you are safe, your soul needs mending and care." (CCN Elisabeth Holmström, 2011)

This quote is one way to express the meaning of intensive care. Intensive care is a young specialty and the first intensive care unit (ICU) was started 1953 in Denmark (1). Since then there have been a rapid and tremendous progress in technology and medical therapy. Today, a population of increasing age and with a significant co-morbidity can be offered intensive care (2). Previously, follow-up after intensive care was merely limited to monitor patient outcome in terms of mortality and physiological parameters, but during the past decade, in parallel with increasing knowledge about patients' experiences of ICU, the interest has become more orientated toward the patients' physical and psychosocial health following the ICU stay (3). Current research has illuminated that former ICU patients have both physical and psychosocial problems which both prolong the time to recovery and decrease health related quality of life (HRQOL) (4, 5). To address these new insights and to support former ICU patients, follow-up clinics have been developed. These clinics intend to help the patients understand their ICU experience and enhance recovery (5). However, to date, there is only sparse knowledge about which patients who will benefit the most from a follow-up clinic. Likewise, it is not known when or for how long patients need to be followed up or what tools to use in the efforts to assist in the recovery process.
To gain insight in these problems there is a need to develop tools for caregivers to use in the follow-up. A questionnaire adapted to the specific situation of critically ill patients could substantially enhance the ability to detect problems during the recovery and also help to identify patients suitable for follow-up. Another tool in the patients' recovery is an ICU-diary. Today there are few common guidelines (6, 7) for how the ICU-diary could be designed and the patients' preferences about its contents. Neither the follow-up nor the ICU-diary is based on evidence which leads to that the care not being based on best

available science, clinical experience and patient preference, evidence-based care (EBC). Therefore, more insight in these matters is paramount to enable better assessment and aid of the patients in the recovery after intensive care. There is a need for increased knowledge to be used for development of evidence-based guidelines to be used by nurses in the clinical work. Evidence-based nursing (EBN) ensures patient-safe care and a higher quality of the care (8).

Background

Intensive Care Context

Intensive care environment

The Swedish Society of Anaesthesia and Intensive Care (SFAI) define "intensive care is to prevent and treat failure in one or more organ systems so that continued life can be meaningful from the patients' point of view" (9 p 3). Dependent on patient group and the ICU location in the world, ICUs are organised in many different ways (10). In Sweden the ICUs have between six and twelve beds and both single and shared rooms are common. The staff stays with the patient around the clock and the patient is never left alone. Most of the patients are acutely admitted to ICU and are not prepared for the high technological environment. The ICU has been described by patients like an unknown, incomprehensible and sometimes frightening environment (11). To treat the patient, advanced medical equipment is necessary. Monitors, ventilators and pumps are located around the bed and the patients are tied to the bed by the equipment. The patient is continuously exposed to light and sounds from the machines (12, 13). The equipment can be experienced as stressful but also give a feeling of safety and security (13).

The critically ill patient

Patients admitted to an ICU usually have a critical condition. Most of them need support with e.g. respiratory, circulatory or renal function. The critical illness itself, different medications, disturbed sleep, equipment, tubes, endotracheal tube and the environment make it mentally and physically

stressful for the patient (14). Usually, patients are sedated to reduce the stress symptoms. Recently, the trend for sedation routines has changed (15). Today the sedation target is to sedate to a level of comfort and as a result the patients are more awake. There is little knowledge about how this affects the patient's memory from ICU (15, 16). Different sedatives and analgesics are used. Most of them provide a state between wakefulness and sleep and may predispose for hallucinations, delusional memories and they can also give amnesia (16). This affect on the memory is an important difference between critically ill patients in ICU and patients cared for in other clinics. Critically ill patients describe that the memories from the intensive care stay vary from no memories at all, to memories from the whole stay (17, 18, 19, 20). A lot of research describe that patients can have delusional memories, nightmares from the ICU stay which can be scaring (19, 20). Delusional memories can seem like factual events for the patients and be hard to understand that they are not real (21). Jones et al. (22) found an association between having delusional memories and no factual memories and development of post traumatic stress disorder (PTSD) related symptoms and conclude that having even unpleasant factual recall can give some protection from anxiety and later development of PTSD related symptoms (22).

Critically ill patients feel vulnerable and also that they lose control. The patients experience that they can not meet their own needs and are not always capable to communicate this to the nurse. Not being able to communicate in this situation leads to anxiety and distress. Families and nurses have an important role to inform, communicate and being there by the bedside to make the patients feel comfortable and secure (13, 23).

Critically ill patients have an increased need for rest and sleep, but the normal circadian rhythm is disturbed and the patients have no possibility to get a normal pattern of sleep (24). A variety of causes like lighting, noise, conversations, nursing interventions, nightmares, pain and alarm from the equipment are some of the reasons affecting the sleep. Lack of sleep leads to cognitive changes and psychological distress (13, 15, 23, 24, 25).

Delirium is a common brain dysfunction in critically ill patients and is associated with poor outcome. Critically ill patients are at high risk to get delirium due to a multiple risk factor. Delirium is a disturbance of consciousness and cognition that develops rapidly and fluctuates over time (26,

27). When hyperactive, the patients try to self-extubate, remove catheters and turn around in the bed (28).
Severe weakness is a common complication in ICU patients and critical illness polyneuromyopathy is one finding that can explain the weakness. Due to catabolism and malnutrition the patients loose about 2% of their muscle mass every day (29). Sedation and the critical illness prevent mobilisation and the immobility leads to decline muscles atrophy and muscle strength (29). When the patients leave the ICU for a regular department many have residual physical and psychosocial limitations.
To prevent physical limitations, rehabilitation has to begin already in the ICU. Recent studies report that early mobilisation and occupational therapy in the ICU are safe for the patient, improve the physical function and reduce the frequency of delirium (30). Patients' recovery has to start in the ICU and there has to be an individual plan where the whole team is included. Both physical and psychosocial needs have to be detected, supported and assessed during the patients care process from ICU to the ward and home (31).

Physical problems after intensive care

The patients' physical health is decreased after ICU. Immobility, muscle-waste, muscle weakness, fatigue, critical illness polyneuropathy are some of the most influencing factors. Some of these problems are related to the mechanical ventilation and length of stay in the ICU (18, 29, 32, 33, 34). If patients have few recalls from ICU and not know how critically ill they have been, the understanding for why they are weak and exhausted are limited. This can lead to unrealistic expectations about the recovery (18, 29).
Other common reported physical problems after ICU are breathlessness, sexual dysfunction, loss of appetite, pain and change in appearance (18, 29, 32, 34). Without an explanation this can be very distressing for the patient. The decrease in physical health affects the patients' daily life in many ways and the dependency on others increases (35). Critically ill patients have generally lower Quality of life (QOL), especially in physically domains even years after ICU (36, 37, 38). In a recent study using Short Form 36 (SF-36) the patients score very low in the role physical domain due to limitations in bending, lifting and climbing stairs (35).

Sleep disturbance during ICU is a commonly described problem and this continues after ICU. Problems with insomnia, nightmares, waking up and not falling back to sleep can all lead to psychological distress (24). Various physical problems occur after the critical illness and affect the patients both psychologically and socially and limit their ordinary lives.

Psychosocial problems after intensive care

Psychosocial problems after intensive care are common. The severity varies from mild symptoms to the development of diseases with a psychiatric diagnosis. A possible reason for some of the problems can be that patients have no structured memory from the whole ICU stay but instead have memories of nightmares, hallucinations and delusions (18, 19, 20).

Patients with no factual memories have an increased risk for developing PTSD (22). Other risk factors are if the patient is young, female, have pre-hospital psychological problems, higher doses benzodiazepine administration in ICU and memories of frightening or psychotic experiences. The prevalence of PTSD related symptoms in ICU patients is high. Three to six months post ICU diagnosed PTSD occurs in about 2-25% and has a high impact on QOL after ICU (39, 40, 41). As diagnostic criteria of PTSD following symptoms must exist; first an exposure to a traumatic event, and also three cluster of symptoms, avoidance/numbing, intrusive recollections (e.g. flashbacks, nightmares) and hyperarousal symptoms (e.g. irritability, difficulty to sleep and to concentrate). The symptoms cause problems in the patients' life in terms of social isolation, not going back to work, or problems in other important social activities (42). Lack of factual memories and uncertainty of the recovery can predispose to emotional distress leading to social isolation expressed as avoidance, depression and anxiety (40, 43). Studies have shown that it is complicated to isolate which factors that have implications on the psychological distress. Unpleasant memories from ICU, length of stay and pharmacological and ventilator treatment are such examples (15, 22, 40). Patients' pre-morbid psychological health and personality also influence the psychological distress after ICU. Coping with the critical illness is easier for patients with an optimistic personality and this helps the recovery to go more rapidly (44).

There are different instruments to measure psychological distress. The most commonly used in ICU patients are Hospital Anxiety and Depression Scale

(HADS) for measuring moods of anxiety and depression. HADS contains one subscale for anxiety and one for depression which then are combined to a full-scale HADS score (45). Another instrument is Impact of event scale (IES) (46) measuring avoidance and intrusion. Avoidance includes symptoms of denial of the events, awareness of emotional numbness and blunted sensation. Intrusions include symptoms of unwanted thoughts and disrupted sleep. The prevalence of anxiety varies in different studies between 12-50% and depression about 25% and high levels at IES is seen in 14-16% (34, 40, 41).

Cognitive dysfunction after ICU is described in several studies with different patient populations e.g. Acute Respiratory Distress Syndrome (ARDS), sepsis, postoperative patients, general medical ICU. Several causes e.g. hypoxia, hypotension, sleep deprivation, sedation have been proposed for the patophysiology. The incident of cognitive dysfunction varies and some studies show that the dysfunction can be persistent and even permanent. The deficits can be problems with memory, concentration, mental processing speed and executive functions which impair social, daily and occupational functions. The consequences of the cognitive dysfunctions result in dependency on help from others like relatives (18, 24, 47, 48, 49, 50). Prevalence of psychosocial problems after critical illness related to the stay in ICU signals further needs to support these patients during their recovery.

Critically ill patients' recovery

The critically ill patients are a heterogenic group, with different diseases and length of stay in ICU. During the ICU stay patients are subject to many medical and caring interventions which have physical and psychosocial effects after ICU. Recovery after critical illness can be a long and difficult process (43). Critically ill patients' recovery process differs from other patient groups because they have varying factual and unreal recollections from the ICU (43, 51). The process initiated in the ICU continues when transferred to the ward and then home. When leaving ICU for the ward the patients can have feelings of incapacity and worthlessness due to physical weakness and fatigue, not knowing why they feel this way. Neither do the patients know about the critical illness or what happened to them in ICU (43, 52). The patients have a need for information to construct a narrative story to help them move forward from passively to empowerment with control of their lives (51). Even though the

information is important it is stressful to gain insight how critically ill they have been and perhaps even been and maybe close to death (43).
Recovery contains different dimensions and to achieve recovery after critical illness, there has to be an improvement in the various dimensions. The dimensions such as clinical; how the patient experiences the symptoms, learn to understand the symptoms and effect on the daily life. The physical; having a healthier lifestyle and diet. The existential; give hope and empowerment, give help in understanding the situation to cope with it. Patients are therefore in need of support from the family. The social and functional recovery; isolation is common and it is important to regain social roles, and to reintegrate back into the community i.e. going back to work or school (53).

ICU Follow-up

Responsibility to follow-up

Being critically ill and treated in ICU is associated with multidimensional residual problems and complications of various duration affecting the patients' life, recovery and QOL (54). Earlier, the responsibility for the follow-up during the recovery process mainly belonged to the general practitioners or health care centres with no involvement from the ICU teams (54, 55). However, patients find that the support is not appropriate and that more information and guidance are needed (56). As the critical illness has a diffuse start and does not end in ICU it is recommended that the patient is followed up by the same team, ensuring that coordination of the patient's need for rehabilitation is appropriate (54, 57). Support and information are important during the critical illness and in the recovery process (57, 58). This support is best provided by the ICU team, who has the knowledge about the patient's situation and the impact of the critical illness (54, 55, 56).
The multidisciplinary ICU team does not see the patient in a biomedical model, instead the team have a holistic approach following the patient from the ICU until after leaving hospital and helping them in the recovery process.

An ICU-diary over the ICU stay

An ICU-diary is a notebook of written text and sometimes contains photos describing the patient's stay in ICU. The first known diary in Sweden was started 1991 and did not include photos. Currently, ICU-diaries are used in Scandinavia and several European countries (6). ICU-diaries are implemented as an initiative originating from nurses, usually without any evidence-based knowledge on how the ICU-diary affects the patient's well-being (59). The ICU-diary is described as a debriefing tool, to fill in memory gaps, to bring time back, sort delusional memories and a help in the psychological recovery (6, 51, 60). A diary is a personal book written from person to person sharing feelings and hope (61). The diary starts when the patient arrives in ICU and, if not, there will be a summary over the time until the day the ICU-diary start. The staff and sometimes also relatives write daily notes all dated and signed (6, 59). This gives the patients an opportunity to get a time-perspective and a chronology of the series of events.

The written material in the diary describes daily activities, visitors, and changes in the condition, even describing uncomfortable and negative events. The patients need to know what happened and reading the diary helps the patients to remember. It evokes memories and feelings, sounds and noises which are associated with specific events (60, 62, 63). Missing data in the diary and events which the relatives tell the patient, can lead to disappointment (64, 65). Even photos have to cover the whole ICU stay to illustrate the progress seen in the photos (65). Photos from the environment, the equipment and of the patient with the tubes confirm the written data and give a deeper understanding (60, 63). Patients describe different feelings like fear, disgust, interest, and unreality when looking at the photos. The diary seems to have many roles for the patients. It can help them to understand how critically ill they have been, that recovery takes time and make sense of what happens. The written data give the patients ability to discriminate real events from their dreams. The photos give a more robust and complete picture and, together with written text it can give a coherent narrative story over the critical illness and time in ICU (60, 62, 63). The diary can be a tool in the patients' recovery as the patients can read it over and over again which may reduce the distress. A recent study shows that patients having an ICU-diary have a lower incidence of new-onset PTSD (6). The result in Jones et al., confirms a beneficial effect of keeping an ICU-diary

(6). However, common guidelines for the content of the ICU-diary are needed to ensure that it can be used as an aid in the recovery process.

Follow-up after ICU

A follow-up program after discharge from ICU is important to early detect sequelaes after the ICU and to inform the patient about the critical illness and what to expect during the recovery process (18, 31, 54, 58). Today, there is no raw model for how a follow-up program should be designed. Different models of follow-up clinics exist, led by a nurse, physician or a multidisciplinary team, which support the patients in the process of recovery (31, 54). An important factor for a follow-up visit is to have an opportunity to discuss concerns about the illness, time in ICU and rehabilitation with the staff. Receiving information from those who have knowledge about caring for critically ill patients helps the patients to understand and make sense of the experience (55, 58). Even if the patients get information from other services or their relatives this is not equivalent (66). Today, there are few guidelines about follow-up programs and what to be included in the program. In UK, the National Institute for Health and Clinical Excellence (NICE) has developed a model of follow-up program with guidelines for professionals to use in the follow-up of former critically ill patients. The program includes guidelines for when and how the support and rehabilitation should be done. The recommendations about the preferred time for follow-up are a visit at the ward and then a visit two-three months post-ICU. Previously, research about follow-up visits shows that both the time for the first visit and the frequency are variable, depending on patients and routines. Which type of patient who has a need for follow-up is not known, some patients only need one visit in the follow-up clinic and some more or none (31, 66). There is a need to obtain more knowledge about the optimum procedure and time for the follow-up.

Measuring recovery for former ICU patients

An increased interest to follow up patients has led to the development of a variety of scoring scales in order to measure outcome (67). Today, there are ICU clinics that regularly use these (Table 1) as tools in the follow-up after ICU. There are difficulties with this, as most scales are not designed for use on

former critically ill patients which can bias the results and affect the quality of the measure (67). The normal progress rate of the recovery is not known and factors independent of the critical illness like socio-economical factors e.g. divorce, unemployment, can affect the outcome. Another difficulty is, that to detect changes there has to be a baseline to compare with and as most patients are acutely admitted, there are considerable difficulties to establish such a baseline. It is recommended that assessment of health related factors and progress of recovery is done by the patient as substantial discrepancies otherwise arise if the same assessment is done by staff or relatives (68).

Patients who have been critically ill and cared for in ICU have lower QOL than the general population. Follow-up studies show that patients have physical and psychosocial problems after ICU, affecting daily life and reducing QOL. Different instruments are used to measure QOL after ICU (38). Using the focus of the three dimensions; physical status and functional ability, psychological status and well-being and social interactions are called health related quality of life (HRQOL) and is a multidimensional perspective of health commonly used in health care measurements (68). Many psychological and social factors influence HRQOL and QOL but physical impairment with disability has a greater influence than e.g. demographic and psychological factors. Assessments of HRQOL give the health care providers knowledge about which patients have better or worse HRQOL and how much it changes over time (38).

However, information on how and in what way the critical illness has an impact on the individual patient is limited. Therefore there is a need for a disease specific instrument to assess the individual patient's problems and needs.

Instruments can be divided into; domain specific, generic and disease specific. A domain specific instrument measures one specific domain, for example to determine the psychological function (68). Instruments like IES-R, HADS, ICU memory tool or PTSD 14 (Table 1) are used for these purposes. A generic specific instrument measures health profiles including the physical, psychological and social dimensions. The instruments are used to compare differences and similarities between groups and interventions (68). Examples of different generic instruments are NHP, SIP, SF-12, SF-36 and EQ-5D (Table 1) all of them used in critical care research, (69) but the generic instruments have to be completed with disease specific instruments to detect clinical changes. The disease specific instrument is designed to measure patients'

perception of a special disease or health. They are clinically relevant and sensitive to assess changes in health, related to interventions (68). The follow-up clinics have a variety of instruments available to use to measure functional status and QOL but none measures specific problems that patients may experience on an individual basis. A visit to a follow-up clinic can help to identify these problems and to support the patients in the recovery process (70). When resources are limited, there are needs for a questionnaire to identify those patients who need the most a follow-up and thus enable resources to be adequately allocated.

Table 1. Instruments commonly used for former ICU patients to perform assessment of problems related to ICU stay and QOL after ICU.

Instrument	Author, Year	Type of scale	Number of items	Assessment aim
Impact of event scale Revised IES-R	Weiss DS, Marmar CR. (46)	Domain	22	To assess current subjective distress related to a specific event
Hospital Anxiety and Depression Scale HADS	Zigmond AS, Snaith RP. (45)	Domain	14	To assess anxiety and depression
ICU memory tool	Jones C, Humphris G, Griffiths RD. (71)	Domain	14	To assess the patients' memory from ICU
Post Traumatic Stress Syndrome PTSS 14	Twigg E, Humphris G, Jones C, Bramwell R, Griffiths RD. (72)	Domain	14	To assess post traumatic stress
Sickness Impact Profile SIP	Bergner M, Bobbitt RA, Kressel S, Pollard WE, Gilson BS, Morris JR. (73)	Generic	136	To provide a descriptive profile in a person's behaviour due to impact of illness on everyday life
Medical Short Form SF-12	Ware, Jr, J. E., Kosiniski, M., Keller, (74)	Generic	12	A shorter alternative to SF 36 assess physical and mental health
Medical Short Form SF-36	Ware J, Snow K, Kosinski M, Gandek B. (75)	Generic	36	To assess generic health concepts relevant across age, disease, and treatment groups
EuroQol-5 Dimension EQ-5D	The EuroQol group (76)	Generic	5	To assess health outcome from a variety of interventions for evaluation allocation monitoring
Nottingham Health Profile	Hunt S, Mc Ewen J, McKenna S. (77)	Generic	45	To assess perceived distress related to severe or potentially disabling health conditions

Conceptual standpoints

Health and illness

The World Health Organization (WHO) definition of health from 1948 says "Health is a state of complete physical, mental and social wellbeing and not merely the absence of illness or infirmity" (78). Critically ill patients treated in an intensive care unit have usually residual problems after their stay and the possibility for reaching health according to WHO's definition is therefore limited. Instead, research shows that the problems have multi-factorial causes and patients' health is impaired in one ore more dimensions long time after discharge from ICU (79).

Theoreticians have tried to define health for a long time starting in the ancient Greece with Hippocrates (460-370 f.kr) and Platon (428/427-348/347). The medical theory is based on the belief that diseases have a natural cause. Health and illness are placed in a holistic approach, where the body is in interaction with the individual's environment (80). The definition of health has changed over time and today there are two different directions; the biomedical and the humanistic (81). In the biomedical direction health is the opposite of illness. Boorse developed the biostatic theory. This theory states that health is absence of illness. There are reductionists who mean that the focus is on the biological body and not the human being and the patients' symptoms and problems are viewed from this standpoint (81).

In contrast to this, theories representing the humanistic approach have a holistic view of man; the human is active and creative and health arises in an interaction between the individual and the context where he or she lives. A holistic approach of health includes many dimensions and aspects like; physical, mental, emotional, psychosocial, social, environmental which interact with each other (81). The former critically ill patient should preferably be seen in a holistic approach where the different needs have to be met by the multidisciplinary team. Today the patients' outcome after ICU usually is obtained by measuring HRQOL with SF-36. HRQOL includes different dimensions and gives a multidimensional perspective of health (68). Critically ill patients have a lower HRQOL than an age and gender-matched population. Measuring of the individual patient's HRQOL can not give the multidisciplinary team information about the specific needs to obtain recovery, then the instrument

does not have a holistic view since it does not include environmental or social factors (80). In this thesis the holistic view is used to help the patient cope with the experience and limits following the ICU stay to obtain optimal recovery from the patient's point of view.

Biopsychosocial model

Engel (82) introduced a new more complete model for the description of health and illness for use in clinical practice, the biopsychosocial model. Before this, the biomedical model has been the dominant model with a focus on physical causes of disease. This model has limitations due to the dualistic nature of a separate body and mind. The biopsychosocial model views the patient and the illness as an interplay of domains like the biological (physical), psychological (emotions, believes, behavior) and social factors (social context, environment) which interact on different levels and affect the process and outcome of care. The different factors could be fixed or influenced through medical or psychosocial interventions (82, 83). In each of the domains there are fixed factors which are constant e.g. age, education, previous life, health before illness and factors which are changeable. The biopsychosocial model incorporates a holistic approach and it can be used to understand, restore and improve health (82). As recovery after critical illness is a complex process including physical, psychological and social factors a biopsychosocial model, involving the multidisciplinary team, is to be involved. Knowing the fixed factors for former critically ill patients can make it possible to select interventions for an individual follow-up.

Recovery

The terms recovery and rehabilitation are used interchangeably in the literature, sometimes with no distinct difference in the meaning between them. There is no standard meaning of what recovery is and the concept recovery is defined differently dependent on culture, profession or in which context it is used (84). In acute psychological conditions this often means that the patient will return to the state before falling ill (84) and in acute physical settings, the goal for recovery is often described that the patients should return to pre-morbid status. (56, 84) This differs from the chronic condition where the patient rarely can

return to the state before becoming ill. Critically ill patients may belong to both the acute and chronic groups. Within psychiatry, there is new knowledge which has led to a change in perception. Thus, the ambition has swung from providing support described as the professionals' pivotal role in restoring the patients' physical and mental capabilities after injury, also described as rehabilitation to aiding recovery whit focus on the individual's resources and contribution to recovery (56, 85). Recovery is a unique individual process with no endpoint that can be homogenously applied for a group. Recovery is a part of the rehabilitation and patients can undergo rehabilitation without achieving recovery. Rehabilitation focuses on the patients' symptoms and problems and the responsibility for the rehabilitation belongs to the health care system and the society which should help the patient to regain physical and psychosocial function and a good quality of life. Not all patients who have undergone rehabilitation obtain recovery. Recovery is based on the unique individual where all the individual's resources and strengths are considered and the staff's responsibility is to be a mentor in the process to obtain the patients' goal to recovery.

There are many dimensions in recovery like existential, social, physical, clinical and functional. A recovery approach includes integrated biopsychosocial treatment and care. Improvement in one dimension affects the others (53). Recovery is an active process which requires that the patient can have responsibility for the recovery. The patients have the opportunities to choose different ways in the process and are also responsible for the consequences of the choice. Emotionally, it is a way to live a satisfying hopeful life even with the limitations caused by the illness. The recovery involves development of a new meaning and direction of life (56, 84, 85). After being critically ill and close to death the patient gets a new insight in his or her life which strongly affects the patient's appreciation and life satisfaction (56, 86).
The former ICU patients' recovery process is complex and methods to measure and evaluate if the patients have recovered are limited and to a great extent unexplored. Many patients describe that they do not recover to the status they had before the critical illness. Instead, the patients have an individual target set for the recovery (56). When the patients and the multidisciplinary team decide about the amount and nature of support in the process to recovery, an

instrument able to detect and assess progress factors would substantially benefit the process.
To understand the patients' multidimensional problems after the critical illness the biopsychosocial model has to be used. During follow-up different tools (ICU-diary, 3-set 4P) can be used to support the patient. The target for recovery is individual and each patient has to set up a personal goal as the recovery process has no end point.

Evidence-based care (EBC)

Health care should be based on evidence-based medicine (EBM), meaning that the given care is based on best available scientific evidence. Sackett et al (87 p 71) definition of EBM is "the conscientious, explicit, and judicious use of the current best evidence in making decisions about the care of individual patients". This means that the decisions are constructed from the best studies, complemented with other clinical expertise (87). There have been some considerations about EBM. The critics mean that it suppresses the patients' and relatives' experience, engagement and the experience of clinical staff but instead EBM complements the above components and it is one component of the care (87). In the treatment and care of the patient both EBM and EBC have a role then they complementing each other in the process of the care. The multidisciplinary team working together by using the best evidence, clinical experience and the patients' preferences to give a high quality care. In Sweden, EBC has been described as a process and as an approach. During the process a systematic review is done, evaluating, interpreting and applying the results of existing research. The approach describes the willingness to use scientific evidence as a base for treatment decisions (88). EBC means that the nurse has the best available knowledge and clinical experience when analyzing the individual patient's problem. On the basis of this, the nurse, together with the patient selects care and treatment which delivers the results the patients wants and needs (88).
Evidence can be a base for producing guidelines to support clinicians in the care. The use of such guidelines can guarantee that the components of care do not depend on the individual caregiver neither on coincidence but instead it is based on evidence and clinical experience (88)

Today there are no evidence-based guidelines regarding the form and content of an ICU-diary. The use of research and clinical experience can contribute to develop such guidelines. There are guidelines when to follow-up patients after their ICU stay (31, 89) but it is not known which patients when or how many times the patients' needs follow-up.

Rationale for the thesis

Critically ill patients form heterogeneous groups who differ from other groups of patients as the illness often is acute and life-threatening and that the patients can have had delusional memories or loss of memories and memory gaps from the stay in ICU.

Today it is common knowledge that former critical ill patients can have physical and psychosocial problems after the stay in ICU. Different tools have been used trying to help the patients during the recovery process. An aid in this process can be a personal ICU-diary. In clinical practice there are a knowledge gap on how the ICU-diary shall be kept and what content the patients prefer to have in the ICU-diary in order to be useful for the recovery. Therefore there is a need for studies to explore this to increase the knowledge and to develop guidelines for the process of ICU-diary keeping, making it a useful tool during the patients' recovery process.

Today there is an increased interest for patient follow-up. The follow-up has been organized in different ways. Knowledge on which patients who have a need for follow-up is sparse. A valid and reliable specific instrument can be helpful to identify patients who have a need for follow up and when the follow-up shall be done. Being able to identify these patients gives the ICU staff an opportunity to get insight in problems relevant for the patients and to be able to offer help in the recovery process. This new knowledge contributes to give the patients a more individualized follow-up, stressors can be identified and reduced during ICU stay and aid to an improved recovery.

Advanced knowledge about the structure and content of the tools for monitoring and supporting the patients during recovery can be a base when developing evidence-based guidelines. Evidence-based guidelines reduce inappropriate variations in practice and instead promote high quality evidence-based care.

Overall and specific aims

The overall aim of this thesis was to describe and explore the use and content of ICU-diaries and to develop and psychometrically test a questionnaire to detect physical and psychosocial problems for ICU patients in the recovery process.

The specific aims of the studies were:

- to describe and to compare the extent and application of patients' diaries in Sweden in relation to ICU levels and some form of ICU follow-up (study I).

- to identify the preferred content and usefulness of an ICU-diary as described by ICU-patients (study II).

- to develop and test the validity and reliability of a questionnaire for assessing physical and psychosocial problems over time for patients following ICU recovery (study III).

- to psychometrically test and evaluate the 3-set 4P in a larger population (study IV).

Materials and methods

Ontological and epistemological framework

Nursing science is based on humanism and has a holistic view of the human and this is the ontological perspective in this thesis. It is based on both the naturalistic paradigm where reality is multiple and subjective and the positivistic paradigm where reality is objective and generalizable (90). In order to give a more comprehensive picture and thorough picture of the phenomenon both quantitative and qualitative approaches are used in this thesis. Naturalistic inquiries usually use qualitative methods to explore the human complexity and the researcher interacts with those being researched. A positivistic inquiry usually uses quantitative methods in trying to understand the underlying causes and the researcher is independent from those being researched (90).

Former ICU patients' recovery process is complex. The patients are not a heterogenic group and the recovery is an individual process. Recovery is how each individual creates a subjective reality based on the personal experience of the world (ontological). Patients' problems are multifactorial and in a holistic view the whole patient has to be seen in an environmental and social context. In the biopsychosocial model the different parts biological, psychological and social and the interaction between them are seen in a holistic view of the human (82). A humanistic view of the human being implies a faith that he or she has a will and an ability to evolve. The biopsychosocial model forms the basis for approaching the phenomenon in this thesis when trying to understand and get knowledge about the patient's recovery process and tools to use in this process.

Epistemologically an inductive process has been used in study I and II. To get a more complete understanding of the purpose with keeping an ICU-diary and its usefulness during recovery, a mixed method approach was used (study I, II). Knowledge in mixed method approach is a mix or combining of quantitative and qualitative approach in a single study. Using both approaches makes it

possible to maximise the strength and minimise the weakness in each method (91).

A deductive process was used in study III and IV when developing a questionnaire based on observations from clinical practice and previous knowledge to detect and evaluate the individual patients problems post ICU. Psychometrical tests and modifications of the questionnaire to achieve the best relevance to former ICU patients' problems, produced a knowledge that can be used in a generalized fashion when approaching these patients and can be used for the individual patient's follow-up.

Study design

This thesis had an explorative descriptive and methodological design. An overview of the studies is shown in table 2.

Table 2. Overview of the study design, the participants, data collection and data analysis

Study	I	II	III	IV
Design	Explorative descriptive with qualitative and quantitative approach	Explorative descriptive cohort with concurrent mixed method approach	Methodological design, Instrument development	Methodological design based on a psychometric evaluation of 3-set 4P
Partici-pants	All Swedish ICUs n = 86	115 former ICU patients having received an ICU-diary	39 former ICU patients	421 former ICU patients
Data collection	Semi-structured interviews by phone	Questionnaire followed of interviews	Newly developed questionnaire 3-set 4P and Medical Short Form 12 (SF-12)	Developed questionnaire 3-set 4P and Medical Short Form 36 (SF-36)
Data analysis	Latent content analysis, descriptive analysis and comparative method	Descriptive statistics, descriptively by content, manifest content analysis	Descriptive statistics and psychometrically tests; for validity and reliability	Descriptive statistics and psychometrically tests; for validity and reliability

Participants and settings

Study I

The Swedish intensive care register (SIR) was used to define all ICUs in Sweden (2007-2008) a total of 86, divided into University (n = 31), County (n = 26) and District (n = 29) units. The ICUs were contacted and staffs responsible for diaries and ICU follow-up were invited to participate in the study. After given consent, information was sent by email and then the interview was conducted by telephone.

Study II

Between 2008 and 2010 four Swedish general ICUs (two University, two county) participated in the study. All ICUs kept diaries and had follow-up clinics but used different policies and procedures for this. The sample in the study was generated from a post ICU database. Including criteria were patients aged 18 years or older and with a length of stay 24 hours or more in ICU. Excluded patients were those with no address or living abroad. The sample was a part of study IV and patients who had responded to a questionnaire (3-set 4P) two months after discharge from ICU were contacted by mail six months after discharge from the ICU. The mail included the same questionnaire (3-set 4P) again and a supplementary questionnaire on the diary. A total of 320 responded to this second questionnaire and 115 had received an ICU-diary from their ICU stay and answered the diary questionnaire. From this sample (n = 115) patients with a length of stay 4-10 days and photo in the diary, were selected for an interview. The choice of time was based on a preferred median length of stay. The reason for this was that the patients should have a diary with an acceptable content. A total of 33 patients fulfilled the time-inclusion criteria and were contacted by mail, of these 15 wanted to participate in an interview (Figure 1). The patients chose where the interview was to take place.

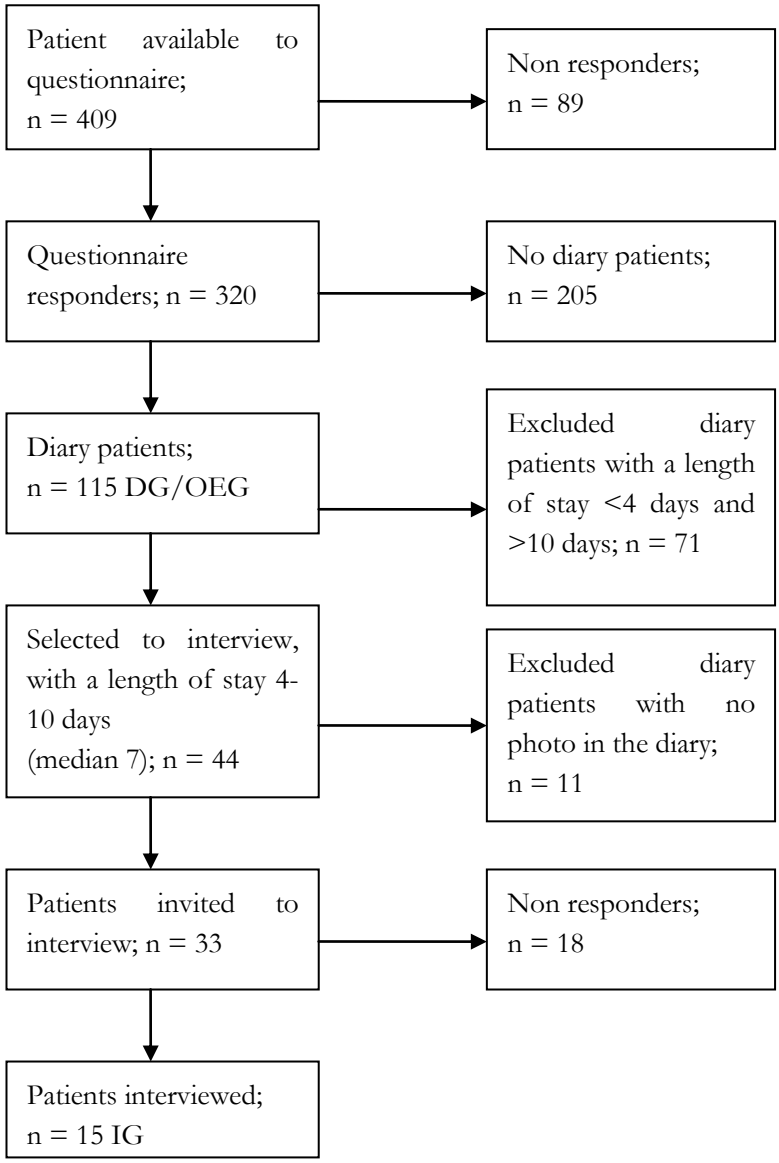

Figure 1. Study flowchart of the data collection procedure among ICU patients. DG = photo-diary group; IG = interview group; OEG = open-ended question group.

Study III

The hospital register at two general university ICUs in south of Sweden (year 2004), was used to select consecutive patients, discharged two (n = 16), six (n = 16) or twelve (n = 17) months after ICU. Patients with a length of stay in ICU >24 hours and >18 years were included. A total of 49 patients fulfilled the criteria and 39 (58% men) responded to the questionnaire. The responders' median lengths of stay in ICU were three days and two days of ventilator treatment. Mean age was 60 years and mean Acute Physiologic and Chronic Health Evaluation (APACHE II) 18.5. In a second round (test-retest) 18 patients from one ICU were included with 17 responded, distributed on two groups with six responders (2 and 6 month) and one group with five (12 month).

Study IV

The study was carried out between 2008-2010 at four ICUs in the south of Sweden, two university and two county hospitals. All ICUs had post-ICU follow-up and kept diaries but used different routines for this. All patients 18 years or older and a length of stay in ICU >24 hours were included, 421 (45%) accepted to participate. There were no significant differences regarding age, sex, SAPS III and time on ventilator between responders and non-responders (n = 510). Admission diagnoses and length of stay in ICU showed significant differences (Table 3).

Table 3. Demographic and clinical data regarding responders and non-responders to the 3-set 4P questionnaire.

	Responders (n = 421)	Non-responders (n = 510)	*P*-value
Sex: Men (%) [a]	254 (60%)	312 (61%)	ns
Age mean (SD ±)[b]	68 (± 15)	62 (± 19)	ns
Time on ventilator, hours, median (p25-p75) [c]	20 (00/75)	19 (00/68)	ns
Hours in ICU median (p25-p75) [c]	67 (41/139)	52 (35/112)	0.002
SAPS III, mean (SD ±) [b]	56 (± 14.3)	56 (± 15.5)	ns
ICU admission diagnosis: (%)[a]			0.014
Multitrauma	31 (7%)	44 (9%)	
Sepsis	55 (13%)	49 (10%)	
Gastrointestinal	47 (11%)	56 (11%)	
Respiratory	94 (22%)	104 (20%)	
Cardiovascular	74 (17%)	59 (12%)	
Periphery vessels	19 (4%)	27 (5%)	
Neurological	15 (4%)	34 (7%)	
Other	86 (20%)	137 (27%)	

p = percentile, SD = standard deviation, SAPS = Simplified Acute Physiology Score. [a] Chi-square test, [b] Student's t-test, [c] Mann-Whitney test

Developing and testing 3-set 4P

In study III a questionnaire to measure former ICU patients' problems and needs during recovery was developed. The questionnaire was called 3-set 4P, as it explores three dimensions 3-set; physical, psychosocial and follow-up regarding former ICU Patients' Physical, Psychosocial Problems, i.e. 4P. The 3-set 4P was based on a literature review, theoretical knowledge and clinical nursing experiences from ICU patients' recovery. A five point Likert scale with closed-ended questions was used to measure agreement. There was one option to answer "not relevant" if the patients had the problem before the critical illness. In study III there was a possibility to respond in own words but only a few used this opportunity. In study IV where 3-set 4P has been further

developed this opportunity was not possible. The questions in 3-set 4P had been modified due to the psychometrical tests in study III.
In study IV questions and response alternatives were changed to a similar layout and the follow-up set was complemented with new questions to obtain a deeper understanding of this area. In study IV one question from set "psychosocial" was moved to background-questions and the set "physical" has been complemented with three questions to increase information about physical mobility.
When measuring concurrent validity there was no fully comparable questionnaire with 3-set 4P, among the questionnaire used to evaluate former ICU patients. Because of this, only seven questions from Medical Short Form 12 (SF-12) (92) were used in study III. When testing concurrent validity in study IV Medical Short Form 36 (SF-36) (93) was the recommended questionnaire to be used in ICU patients (54) and therefore 13 questions from SF-36 were used in study IV for similar reasons. Both SF-12 and SF-36 are generic specific and not fully comparable with 3-set 4P.

Data collection

Study I

In study I a semi-structured interview-guide translated from Danish to Swedish and retranslated, (94) validated by five senior ICU nurses, was used. The interview-guide included questions concerning the extent and application of the ICU-diary. Demographic data were collected from both the interviews and from the Swedish Intensive register (SIR). The interviews took 30-60 minutes, conducted by telephone and digitally recorded. Then the interviewer transcribed the interview verbatim and emailed them back to the respondent for verifying or clarifying their statements, as a part of validation.

Study II

A mixed method was used in study II. Information and the diary questionnaire were sent to the selected sample in a prepaid mail. If no response, the patient

was contacted by phone and in cases with no contact a last reminder was sent by mail.

The questionnaire was constructed by the research group included two sections; the written content (18 questions) and the photos (11 questions). Both dichotomous questions and open-ended questions were included. To get a deeper understanding about the phenomenon, 15 patients were also interviewed. These patients were selected from the main group which had answered the questionnaire. The research group constructed an interview-guide with ten open-ended questions, one question "describe what you would like the ICU-diary contain", the content (3 questions), the photos (3 questions) and the usefulness (3 questions). Patients were contacted by telephone for time and place arrangements for the interview. Each interview took between one and one and a half hour. Two patients were interviewed by telephone, seven at the hospital and six in their homes. All interviews were tape recorded and transcribed verbatim.

Study III and IV

Demographic and clinical data were obtained from the hospital database and from the first part in the questionnaire. In study III the 3-set 4P, SF-12, a cover letter and an informed consent form were sent to selected participants with a prepaid envelope, two months after discharge from ICU. The mail to selected participants in study IV included the same material except that SF-12 was shifted to SF-36. To test the stability-reliability a retest was conducted, in study III the 3-set 4P and SF-12 were sent for a second round one month after the first response. In study IV retest 3-set 4P and SF-36 were sent for the second round one month after the first mail until at least 60 had responded.

Instruments used for concurrent validity – SF-12 and SF-36

SF-12 and SF-36 are generic instruments measuring health related quality of life. SF-36 is validated for critical care patients. SF-12 is a shorter form of SF-36 and is developed due to that SF-36 is a voluminous instrument which has been discussed to be too long to use in some populations and research. SF-36 contains eight subscales, physical functioning, role physical, role emotional, mental health, bodily pain, general health, vitality and social functioning, and

SF-12 two. When constructing SF-12 two questions from each of the subscales physical functioning, role physical, role emotional and mental health was included and one from each of the subscales bodily pain, general health, vitality and social functioning. Level of health and the content of health are more deeply assessed when using in SF-36 than SF-12 (74).

Data analysis

Study I

This study was analysed with descriptive, qualitative and comparative methods. The questions in the interview-guide were descriptively analysed. One question "what is the purpose of keeping diaries at your unit?" was selected to be analysed by qualitative content analysis in a latent level (95). The interviews were read several times of the researcher and co-researchers to get a perception of the explained purpose for keeping ICU-diaries. Important meaning units were identified and were condensed to a description close to the text, manifest content. Then the condensed meanings were abstracted due to interpretation of the underlying meaning, latent content into subthemes and themes, answering the question how (95). Questions from the descriptive analysis which corresponded to the themes in the qualitative analysis were analysed with X_2 to describe difference between ICUs at different levels, $p < 0.05$ was considered significant. The result from the latent content analysis was compared with questions from the descriptive analysis of the interview-guide to determine correlation between the purpose of keeping ICU-diaries and the actions undertaken (Figure 2).

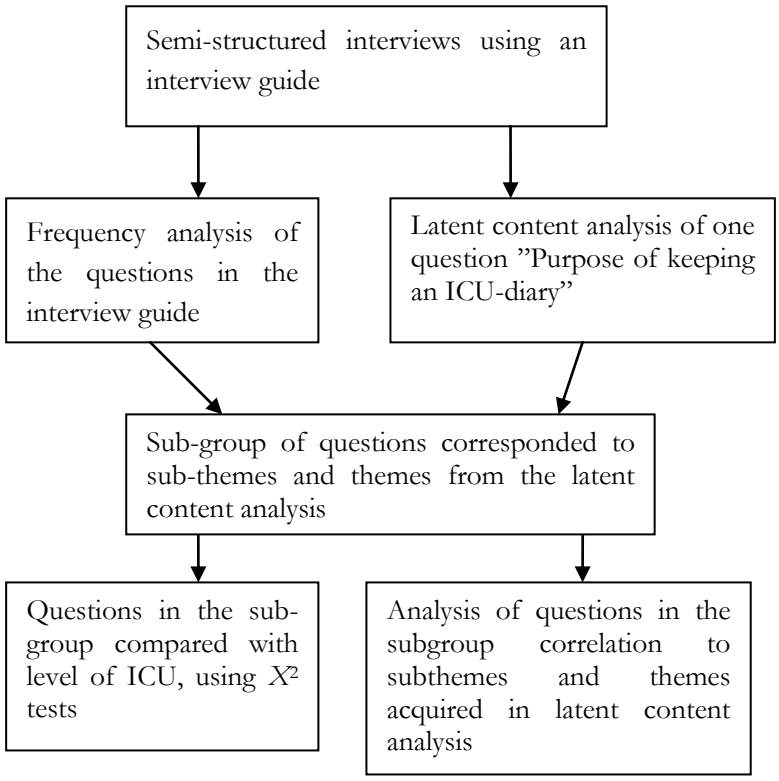

Figure 2. Overview of the analysis process in study I

Study II

A mixed method approach was used in study II to get a broad and deep understanding about the ICU-diary concept. In a mixed method the quantitative and qualitative data are mixed together in one study. The mix of the data can be done in different parts of the study, the interpretation, data collection, data analysis or a combination (96). This study was combined at an interpretive level in the data analysis. The data were collected at the same time, concurrently. Quantitative data were collected from close-ended questions in the questionnaire, analysed with descriptive statistics and the open-ended questions from the questionnaire were analysed by content summarised in categories. The qualitative data consisted of open-ended questions used in the interviews and analysed with manifest content analysis into categories. The

transcribed interviews were read several times to get an understanding of the data and see the visible that the text describes. Meaning units were identified, condensed, coded, abstracted and sorted in sub-categories and categories. Creating categories content belonging to one category can be compared with data which belong to another category. The categories answered the question "what" and gave an increased understanding and knowledge about the ICU-diary (97). Data from the different analyses were then combined to seek convergence in the data, concurrent mixed method (96).

Study III and IV

The statistical analyses were done with SPSS for Windows 15, 17, 19. In study III and IV the 3-set 4P was psychometrically tested. Face and content validity in 3-set 4P were tested by the research group. A pilot test of the 3-set 4P were done with three former ICU patients (in study III) (90). Principal component analysis with varimax rotation were used to measure construct validity in each set, physical, psychosocial and follow-up (98). Kaiser Meyer-Olkin (KMO) measured how much a question's variance overlapped with other questions' variance, >0.6 was required and Barlett's test of sphericity had to be significant ($p < 0.001$). Factors with Eigenvalue >1.0 were included. The questions factor loading <0.4, questions loading >0.9 or loading on more than one factor were excluded (98). Homogeneity was measured with Cronbach's α reach a score >0.7 to be good reliability. In study III item-total in each set were measured. In study IV item-total in each set and inter-item correlation in each factor were measured (98, 99). Concurrent validity was analysed with Spearman's r_s in study III, correlation was compared between seven questions in SF-12 and related questions in 3-set 4P and in study IV between 13 questions in SF-36 and related questions in 3-set 4P. A correlation <0.2 was considered weak, 0.3-0.6 moderate and >0.7 as strong (100). Stability and reliability were measured with Spearman's r_s in study III with >0.5 acceptable. In study IV intraclass correlation (ICC) was used where >0.8 is almost perfect agreement, 0.7-0.8 indicate strong, 0.5-0.6 moderate, 0.3-0.4 fair and <0.2 poor (101). In study IV the ICC was used due to the fact that the problem with getting a good correlation between two tests even if they do not really have acceptable high similarity is less with ICC.

Methodological considerations

Trustworthiness; credibility, dependability, confirmability and transferability in study I and II

Reality can be described in different ways by qualitative and quantitative research. In this thesis different methods were used to evaluate and develop tools to be used in the recovery process for former ICU patients. Multiple designs were used including, in study I, both a quantitative and a qualitative approach, in study II, a mixed method and in study III and IV, a quantitative method. Mixed method is a method describing research where qualitative and quantitative methods are mixed in the same study. Quantitative and qualitative data can complement each other in combination of qualitative and quantitative research techniques, methods or concepts (102).

The quality of the research has to be evaluated. In qualitative research the four concepts credibility, dependability, confirmability and transferability are used to describe trustworthiness (90). Credibility refers to confidence in the truth of the data, how well the data and analysis address the phenomenon (90). Dependability is the reliability stability over time in the study, involving the risk for inconsistency in the data analysis (95). Confirmability refers to objectivity and that the results reflect the participants' responses and not the researchers' perspective of the response (90). If the findings in the studies could be transferred to other groups it is called transferability. Describing the sample, data collection and analysis gave the readers a possibility to decide if the result was transferable (95). In quantitative research concepts as validity, reliability and generalizability are used (90). Validity in quantitative research refers to that the instrument measures what it was intended to measure (103). Reliability refers to the accuracy of information obtained in the study. External validity refers to if findings in the study can be generalised to other samples. Replication of the results in another sample strengthens the external validity (90).

Study I

In study I qualitative data were collected from semi-structured interviews. This allowed the respondent to answer the questions in their own words without being influenced by the researcher. It was a national survey and all ICUs in Sweden were included, which was a strength. Staffs responsible for keeping ICU-diaries in the ICUs were interviewed. Some of the ICU did not have a responsible nurse and then a nurse with vast experience of ICU-diaries was interviewed which could have biased the responses. All interviews were made by the same researcher which can be considered both as a strength and a weakness. The strength was that the questions and interviews were made in the same way and the weakness was that the interviewer got new insight in the phenomenon and this could influence the follow-up questions. Every interview took about 30-60 minutes. The interviews were conducted by telephone which could affect the responders' answer both in making them feel uncomfortable (90) or more free to answer when not interviewed face to face. Mailing the transcribed interviews to the responders' for confirmation the confidence in the data increased the internal validity.

The interviews were carried out by the same researcher, an ICU nurse with experiences of ICU-diaries. This background gave a pre-understanding of the phenomenon which could affect the interviews. Using an interview-guide reduced the interviewers influence on the follow up questions during the interview. During analysis the researcher and the research group tried to consider the confirmability (90).

One question, the purpose about keeping ICU-diaries, was analysed with latent content analysis (95). At a latent level the theme should describe the underlying meaning in the content of the interview text. The research group reflects over the subthemes before formulating them in themes. However, in the published article it was presented as content analysis on a manifest level. This error has been overseen by both the research group and the editor of the publication.

In the analysis process three members of the research group analysed the data and then the research group whit a multiprofessional composition reviewed the data independently. This strengthens the dependability of the study.

A theme is the underlying meaning in the meaningful units answering the question "how". During the analysis process meaningful units were sorted and create subthemes and themes (95). The theme "the individualized care"

provides only one subtheme "a tool in the rehabilitation" which covered the meaning in the condensed text. The research group found the result important to describe the phenomenon although it can be discussed whether a theme only has one subtheme.

Study II

In study II a mixed method was used. The strengths with this method are that the qualitative data makes up for the weakness to understand the context in what has been told in the quantitative data and the quantitative data make up for the weakness of the qualitative. There could be a stronger convergence and corroboration for the conclusion making the results transferable (90). Using both quantitative and qualitative method gives a deeper understanding of the phenomenon. It gives a greater validity when the quantitative results can be confirmed by the qualitative results. The quantitative results in study II gave descriptive information about the ICU-diary, which in an analysis of the qualitative results gave a more complete and deeper information of the ICU-diary. On the other hand there are some limitations with mixed methods. Mixing two different methods is practically more complex. Another weakness is the difficulties with handling of both quantitative and qualitative data phases concurrently by one researcher (90).

The participants who responded to the questionnaire had less homogeneous demography which contributes to a variation of the ICU-diary under study. In the selection of the sample for interviews the inclusion was chosen from the mean LOS around the responder to the questionnaire. The time was chosen so that the patients should have an ICU-diary containing an appropriate content. Perhaps there would have been a better demographic variation of the participants if all patients with photos in the ICU-diary had been selected. In the interview a semi-structured interview-guide was used, which allowed the respondent to answer the questions in their own words without being influenced by the researcher. The data were analysed by the research group which had a variation in the composition consisting of two ICU-nurses, one anaesthetic nurse and an ICU-physician, this was a strength in both the qualitative and quantitative analysis process. The same researcher did all the interviews and this could influence the data collection in the same way as in study I. An ICU nurse with experiences of ICU-diaries had a pre-understanding

in the phenomenon which could affect the interviews. During analysis the researcher and the research group tried to consider the confirmability (90). Content analysis in a manifest level was used when analysing the interviews. Using manifest level differs from study I where the underlying meanings from the analysed interviews were conducted. When the themes and categories in study I and II are compared they look similar, although there is a difference. The themes in study I gave an understanding about the purpose of how the ICU-diary could be a tool for the patient during recovery and in study II the manifest analysis gave an understanding of what content the ICU-diary should cover to be a tool in the recovery. The statistical analyses were discussed with a statistician and by the research group to promote objectivity.
Interviewed patients had also answered a questionnaire, which, in a larger sample confirmed what the patients described in the interviews (95).

Validity, reliability and generalizability in study III and IV

A threat to the internal validity can be the non-responders who appeared in study IV. A comparison between non-responders and responders to identify possible significant differences were made. Non-responders had less time in ICU. No other significant differences were detected.

Study III and IV had a methodological design where a questionnaire was developed and psychometrically tested. When developing a new instrument different aspects of validity such as face, content, concurrent and construct have to be explored (103). A description of the questionnaire development process has been made in study III and IV. Face and content validity means that the contents of the constructed questionnaire should be representative of what is to be investigated, the phenomenon, and that the questionnaire is appropriate for those who will respond (103). The 3-set 4P was developed and psychometrically tested in a pilot study (study III) and then modified and tested in a large sample in study IV. In study III two senior researchers and five senior ICU nurses examined the questionnaire for face and content validity. A pilot study tested the questionnaire with reference to understanding of instructions

and questions. In study IV, the research group and two ICU nurses examined the modified questionnaire.

Concurrent validity examines for example the correlation between a new questionnaire and a previously validated questionnaire. It is used when a new questionnaire is tested in order to replace an existing one, and the questionnaires should be administrated at the same time (99). As no instrument was found to measure the same as the developed 3-set 4P the correlation was weak to acceptable and this could be due to the different type of scales. This may confirm that there is a place for 3-set 4P. Construct validity refers to how the questions in the questionnaire relate to the underlying phenomenon (98). In study III and IV the construct validity was measured with principal component analysis followed by rotation to orthogonal transformation by varimax rotation. There are large discrepancies between recommended sample sizes conducting exploratory factor analysis (100). In the pilot study (III) the sample can be discussed but the result in the factor analysis was acceptable. In study IV the sample size was sufficient when conducting the factor analysis.

Reliability in quantitative research refers to the accuracy of information obtained in the study. There are several methods to test reliability. Test-retest is one method meaning that the questionnaire is administered to the same person on two separate occasions. The results from the different occasions are compared and analysed for correlation (99). Test-retest was used in study III and IV. The time span between the first and second rounds can be discussed due that patients had a faster progress in the recovery process during the first part of the recovery and that this could affect the results.
Internal consistency means that the homogeneity of the questionnaire was tested. It measures how well the questions were related and whether the questions measured the same thing (99). In both study III and IV the homogeneity was good.
If the findings in the studies could be transferred to, for example, other groups it is called generalizability. In study III which was a pilot study, the sample was small. This was a first stage in the questionnaire development and the result was not to be used for generalization. A meticulous description of the questionnaire development process has been done in study III and IV, to enable the reader to decide if the questionnaire could be used. In both study III and IV the

statistical analyses were discussed with a statistician and by the research group to promote objectivity. In study IV the developed questionnaire has been tested in a large sample. Before being used in clinical practice some minor modifications must be done, due to the factor analysis.

Ethical considerations

The research in this thesis followed the ethical principles for medical research on human beings according to the declaration of Helsinki (104) and the national guidelines ethical principles (105). Ethical approval was obtained for study II, III and IV of the Ethics Committee of Health Sciences Faculty, Lund University and permission were obtained from the ICU directors in each ICU. In study I ethical approval was not applicable when staff was interviewed. Permission to conduct the study was obtained from the respective ICU director.

Respect for autonomy

The participants in all four studies have received written information about the nature and purpose of the studies, by mail. In study I and II participants in the interviews also received verbal information. The information included that participation was voluntary, withdrawal from the study could be done at any time without consequence and that confidentiality would be preserved. Participants in study I and II was informed that the interviews were recorded. Participants in study II were informed that there was a possibility to get in contact with a social worker if a need should arise after the interview (90, 105). Study III and IV included information to those who did not want to participate about descriptive information to be used in analysis if there were common factors affecting the generalization of the results. Asking for reason to not participate could be discussed, then each person had the right to self-determination. Background information on all patients was important to the overall interpretation of the findings and therefore this information was obtained.

Non-maleficence and beneficence

Psychological problems that impaired cognitive function and physical weakness have been seen in former critically ill patients. In study II, III and IV questionnaires had been mailed to the patients once or twice, and this could be difficult for some patients to cope with. This was taken into account when the questionnaire was designed, so that the questionnaire was deliberately clear, brief and not too extensive, but still was able to provide the searched information. An ethical problem was that the questionnaire could remind the patient about unpleasant experiences which could lead to emotional distress and need for psychological support. The ethical principle not to harm was followed and the patients were informed that there was a possibility to contact a social worker if needed (90, 105). Another problem was if the researcher in the questionnaire saw responds indicating that the patients had problems that had to be attended. Here, the principle to do well was applied and the researcher should contact the patient, but in this there was a risk that the patient could experience that the researcher violated his integrity. The researcher should have a sensitive attitude in this contact (90, 105).

In qualitative research the need for sensitivity was even greater. The researcher who conducted the interviews in study I and II had an extensive experience of critically ill patients and their follow-up and had education in interviewing methodology. In study I the researcher had, through her professional work made contact with some of the responders before the study. In study II a selected sample from questionnaire responders were interviewed. The patients had answered the questionnaire first and then took part in a follow-up interview. As the interview could be psychologically and emotionally stressful for the patients, the researcher tried to create and open and safe climate during the interview (106). The patients could choose the place for the interview and could have a relative present during the interview. The recent answering of the questionnaire prior to the interview gave the patient a pre-understanding of the interview. The interview could also be a part of the patients' recovery then it gave an opportunity for the patients to talk about their experience and their life situation. To talk about traumatic events over and over again can serve as a therapeutic intervention.

The principal of justice

In research the principal of justice means that the sample was selected in an ethical acceptable manner (90, 105). In study I the Swedish Intensive Care Register (SIR) was used to identify all ICUs in Sweden. All 86 were contacted and those 65 keeping photo-diaries were included. Participants in study II, III and IV were identified from the SIR data-base and all patients who fulfilled the inclusion criteria regardless of social standard, sex or nationality were included.

Summary of the results

Use and practice of patient diaries in Swedish Intensive care units: a national survey (study I)

This study focused on extent and applications of an ICU-diary in Swedish intensive care units. It was common (76%) in Swedish ICUs to keep ICU-diaries for the patients. There was an explicit purpose to keep ICU-diaries and this emerged in three themes, give the time back to the patient, help the patient to remember and individual care. There was no consensus between the ICUs on which patients who should have an ICU-diary. In district ICUs it was more common to select a special patient group like ventilator treated patients, than in university ICUs ($p < 0.05$) where this factor did not reach significance. About half of the ICUs selected all patients regardless of age, level of consciousness and length of stay. Usually the ICU-diary was started after three days, but some ICUs stated that it could take longer time often explained by high workload. There were sometimes guidelines for structure and content in the ICU-diary but these guidelines differed between the ICUs. The ICU-diary was written with focus on the patient and both staff and relatives could write in the ICU-diary. Some had a special diary for the relatives. The content in the ICU-diary varied and it could include medical information, daily activities, environmental issues, equipment and changes in the disease state where some ICUs included all where as others focused on general comments and daily activities. Photos enabling to follow the process were used in 66% of the ICUs and more seldom in district ICUs. Even the kind of photos and what the photos described varied. Some of the ICUs took photos of e.g. wounded body parts, a swollen face meaning that it could help the patient to understand how critically ill they had been whereas others avoided this kind of photos. The legal aspects on keeping an ICU-diary were not clear and most ICUs thought that the ICU-diary was the patient's property and was not considered as an official patient record. The ICU-diary was handed over to the patient when leaving ICU in most cases. Follow-up after ICU occurred in a total of 50% with a significant difference ($p < 0.05$) between county (77%) and university (39%) and district (37%) ICUs. The follow-up was seen as a possibility to follow up the patient but it could also

be used for the development of the ICU-diaries and for improving patient care. A majority of the ICU had dedicated staff for the ICU-diary keeping, and this was predominantly the case (96%) in county ICUs. Overall dedicated staff was responsible for the material and the follow up. Evaluating the ICU-diary concept was done in seven ICUs by using a questionnaire.

The result of how the subthemes and themes from the latent content analyses of "purpose" for keeping ICU-diaries correlated with the corresponding questions from the interview-guide is showed in table 4.

Table 4. Results of the latent content analysis identifying subthemes and themes concerning the item "Purpose" and how these relate to the results in the corresponding set of items defined in the interview-guide.

Subtheme	Theme	Item	Total % yes (n=65)
	Give time back to the patient		
Give the lost time back		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Photo	66.2
Provide information/an image what happened during the care		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Photo	66.2
Fill in memory gaps		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Photo	66.2
Get to know what they have been through		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Photo	66.2
	Helping the patient to remember		
Process the events and memories		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Follow-up	51.6
		Photo	66.2
		Handed over to ward	90.8
Helping the patient to understand		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Follow-up	51.6
		Photo	66.2
		Handed over to ward	90.8
Helping the patient to feel better		Structure	89.2
		All patients	52.3
		Ethic	35.4
		Follow-up	51.6
		Photo	66.2
		Handed over to ward	90.8
	Individualized care		
A tool in Rehabilitation		Research	5.3
		Evaluate	53.8
		All patients	52.3
		Follow-up	51.6
		Photo	66.2
		Handed over to ward	90.8

Preferred content and usefulness of an ICU-diary as described by ICU patients - a mixed method analysis (study II)

A majority of the patients in study II had an ICU-diary which covered the time in ICU. The ICU-diary where written in a chronological order but if there was missing days or photos the patients could not follow the progression. The patients described that they had few or non realistic memories and a memory gap from the ICU stay which had to be filled in order to understand what happened in the ICU. A finding from the interviews confirmed in the open questions was that the patients had to realize how critically ill they had been to really understand what they had been through. The ICU-diary with complete information about both medical and daily events could then be a help when filling in the memory gap and to reconnect to reality. The category "significance of content" described that all data had to be included to get a comprehensive understanding about what had happened (Figure 3). Photos in the ICU-diary appeared in 65% and nearly half of the patients had photos covering the whole ICU stay. When combining photos and written text a deeper understanding of the time in ICU and the critical illness was obtained. Reading the ICU-diary evoked mixed feelings like distress, sadness and being close to death. The photos were not unpleasant to look at but the same patients described that it was unreal as a feeling of alienation like looking at someone else. In order to build a memory there had to be photos from the environment, equipment and staff as looking at the photos evoked pictures in the memory. The patients used the ICU-diary during their recovery process. They shared it with their relatives both in discussions and as a help in communication. Reading it over and over again helped the patient to reconnect and recapitulate what really happened and what was in their dreams. When they had concerns they used the ICU-diary and searched for the information. The ICU-diary gave answers to the questions and gave an understanding which helped the patients further in the recovery process (Figure 3).

Examples of Meaning Units	Sub-categories	Categories
It is like seeing a third person, somehow it is not me although I know it is	To have a feeling of alienation	**Realize the critical illness**
It is hard to understand that I lost a week of my life	To fill in memory gaps	
Has this really happened? You realize how close you are to death, how fragile life can be	To have evoked emotions	
I miss some of the most important medical events in my life	To have incomplete information	**Significance of content**
Medical information helps to reconnect to what happened	To have presence of medical information	
To have a time axis that logically shows the time course of the illness	To get a time context	
That the staff write what happened, e.g. washed my hair	To get a conveying content of daily activities	
Life goes on	To connect to reality	**Usefulness for re-orientation**
To get through, recapitulate so I can understand what has really happened and what is in my dreams	To enhance recovery	
When I describe to friends what happened	To have a tool for communication	

Figure 3. The results of the interviews (meaning units, ten subcategories and three categories) with ICU-patients based on a manifest content analysis.

Development of 3-set 4P questionnaire for evaluating former ICU patients' physical and psychosocial problems over time: A pilot study (study III) and Psychometric evaluation of 3-set 4P questionnaire (study IV)

Construct validity were measured with principal component analysis to orthogonal transformation with varimax rotation in each set of the 3-set 4P. The initial test to measure the sample adequacy with Kaiser Meyer-Olkin (KMO) was 0.761 and 0.533 in study III and >0.6 in study IV and Barlett's test of sphericity was significant p <0.001. Included factors had an Eigenvalue >1.0 and questions factor loading >0.4. In study IV factor loading >0.9 or loading in more than one factor were excluded. The best solution in study III were four factors in set "physical" with explained variance 72.9% and three factors in study IV with explained variance 64.2%. In the set "psychosocial" there were five factors with an explained variance 70.9% in study III and 62.6% in study IV. The third set "follow-up" revealed four factors with explained variance 86.6% and 77.5% (Table 5).

Table 5. Construct validity and internal consistency reliability of the modified 3-set 4P questionnaire in terms of an explorative factor analysis (Principal Component Analysis, Varimax Rotated) and Cronbach's coefficient α. (study IV).

3-set 4P	C	f1	f2	f3	f4	f5	α
PHYSICAL SET:							0.755
Physical limitations							0.715
Physical health today	0.468	0.568					
Limitations in walking	0.733	0.838					
Limitations walking several stairs	0.686	0.821					
Pain affects daily work	0.531	0.723					
Change in appearance							0.666
Appearance	0.600		0.722				
Lost hair	0.520		0.719				
Less muscles	0.562		0.540				
Skin	0.600		0.765				
Physical condition							0.842
Mobility	0.852			0.916			
Physical condition	0.468			0.922			
PSYCHOSOCIAL SET:							0.836
Memory							0.849
Concentration reading books	0.691	0.811					
Concentration reading newspaper	0.754	0.812					
Memory name	0.594	0.758					
Memory daily	0.626	0.741					
Memory event	0.570	0.713					
Mood							0.810
Psychological health	0.580		0.638				
Tearful	0.570		0.731				
Irritation	0.594		0.677				
Depressed	0.721		0.804				
Anxiety	0.488		0.606				
Alone	0.554		0.621				
Social life							0.727
Harmony	0.608			0.757			
Social life	0.630			0.837			

Relation	0.712		0.786			
Avoid						0.535
Avoid places	0.555			0.668		
Avoidance	0.610			0.769		
Sleep						0.716
Back to sleep	0.774				0.859	
Fall asleep	0.733				0.786	
Nightmares	0.521				0.620	
FOLLOW-UP SET:						0.912
Information						0.887
Medical information	0.792	0.833				
Satisfied Medical information	0.841	0.819				
Satisfied care information	0.813	0.796				
Care information	0.661	0.797				
Positive follow-up	0.716	0.702				
Help in recovery						0.831
Help processing	0.783		0.792			
Rehabilitation	0.828		0.686			
Conversation	0.689		0.667			
Understanding	0.756		0.665			
Realizing the critical illness						0.801
Fill in memory gap	0.777			0.772		
Positive diary	0.797			0.678		
Increased understanding	0.735			0.729		
Help with problems						0.888
Help physical problems	0.902				0.896	
Help psychological problems	0.866				0.808	

C = communalities, f = factor loadings, Kaiser-Meyer-Olkin (KMO), physical set 0.748, psychosocial set 0.834, follow-up set 0.815, Barlett's test of sphericity <0.001, Eigenvalues >1.0

Concurrent validity was conducted between SF-12 (study III) and SF-36 (study IV) and 3-set 4P with spearman's correlation coefficient. In study III correlation was strong in three questions and moderate spearman's rho 0.3-0.6, in four and in study IV correlation was moderate in eight questions and weak in

five. All questions except one in study III and two in study IV were significant $p < 0.05$.

Stability reliability was assessed with test-retest one month's interval. Spearman's correlation coefficient was used in study III with acceptable correlation $r_s > 0.5$. In set "physical" eight of eleven questions had acceptable correlation, in set "psychosocial" 19 of 22 and in set "follow-up" two of ten, all acceptable correlations were significant ($p < 0.05$). In study IV ICC were used. In the set "physical" three questions had poor ICC and seven had fair to strong. One question had poor ICC in the set "psychosocial" and seven fair and the rest moderate. Four questions in the set "follow-up" had ICC >0.8 and the other strong to moderate. In the set "physical" questions in both studies with poor or non-significant correlation were similar in character as condition or mobility. In set "psychosocial" there were no compliance between questions in study III with non-acceptable correlation and questions in study IV with poor or fair correlation. In study IV questions included in the factor "social life" all have poor to fair correlation. Comparing in the set follow-up was difficult as the set has been modified between study III and IV.

Homogeneity was assessed with Cronbach's α respectively in each set in study III and study IV, set "physical" 0.7 and 0.75, set "psychosocial" 0.85 and 0.84 and set "follow-up" 0.82 and 0.91. In study IV homogeneity in separate factors was assessed. In set "physical" the three factors gave 0.66-0.84, set "psychosocial" five factors 0.54-0.85 and set "follow-up" four factors 0.80-0.89 (Table 5).

Discussion

In this thesis health is seen from a human perspective where health is not merely absence of disease but involves the presence of different dimensions of wellness. A humanistic approach also involves a holistic approach where the focus is the whole person in interaction with the world (80). Critical illness is a traumatic event that affects the patients' life, both during and after ICU in biological, psychological and social context. The bio-psychosocial model has a holistic approach where the patient's physical, psychological and social problems interact (82) and therefore the composite problem has to be considered when the staff chooses tools for use during the recovery process. Patients who have been critically ill have different needs for follow-up during the recovery process than ordinary patients. This is due to the fact that it is common with loss of memory or few memories from the time in ICU, (18, 19, 20) which affects the patients in different ways and makes it difficult to set up realistic goals for the recovery. Recovery is a multidimensional, individual and personal process starting after ICU discharge and with no defined endpoint. To obtain recovery, a bouquet of different tools is needed. Former ICU patients' recovery process is complex and this thesis discusses the exploration and development of tools for use during the follow-up. The increased knowledge can be used when creating guidelines for tools to be used during follow-up. These guidelines have to be based on evidence to guarantee an improved quality in patient care and outcome.

A main finding is that there are discrepancies in ICU-diary structure (study I, II) and patients selected to have an ICU-diary (study I) which makes the value of usefulness dubious during the recovery. To fulfil the patient's wish to have an ICU-diary useful in the recovery process the content in the ICU-diary must be written in a chronological order covering all information and photos (study II). The results of this thesis point out a need for guidelines for the keeping of ICU-diaries. The findings in study II could be the bases for the development of such guidelines.

To meet the individual patient's need for follow-up there has to be an instrument able to identify which patient, when and for how many times there is a need for follow-up. Today there are no instruments measuring this and the

follow-up program depends on the routines on each hospital. The 3-set 4P, which includes all three dimensions, physical, psychosocial and follow up, can be a useful tool to create guidelines for follow-up.

Being critically ill is a traumatic event affecting the individuals' life during and after the critical illness (107). A part in the process to recovery is to create a story from the critical illness. The story can help to make sense of what happened and set realistic goals. A personally written diary, sometimes with photo, an ICU-diary, can be a help for the patients when creating a coherent story over the stay in ICU (51). The story can be used when coping with the ICU experience (107). The usefulness depends on the content of the ICU-diary (study II). Keeping ICU-diaries are common in Sweden although there is no uniform purpose for these procedures (study I). Today the evidence about ICU-diaries are limited nor is there any guidelines about what content the ICU-diary should have to be useful during the patients' recovery. This is confirmed in study I where different purposes of ICU-diary keeping are condensed in three themes "give time back", "help the patient to remember" and to use in "individualised care". These themes reflect different dimensions of the ICU-diary. There are also different rationales for keeping ICU-diaries like it can be therapeutic, caring, and emphatic or a mixture of these (108). This is in agreement with the above described purposes identified in study I, although few studies describe the patients' opinions about what content an ICU-diary should include to become a useful tool in the recovery and not only something nondescript which might be interesting to read. If the different purposes reflect the content in the ICU-diary, it depends on which hospital and the routines for keeping ICU-diaries what kind of ICU-diary the patient gets. There are discrepancies between the purposes, give time back reflects that the patient gets information about what happened, help the patient to remember reflect that the patient not only gets information but also gets a deeper understanding about the critical illness and individualised care reflects that the ICU-diary can be a tool for e.g. communication. By searching for evidence a purpose including all the aspects can be found and keeping ICU-diaries can be used in EBC.
The lack of guidelines about the content in the ICU-diary as seen in the theme "Give time back" or filling in memory gaps. When creating a story about the ICU-diary it had to include more detailed information and events to become useful. To be able to fill in the memory gaps, to get information and knowing

what happened it was important that there was a chronology in the notes and photos. The chronology was important due to that a story with chronological and experimental time gives temporal coherence and decreases the disorientation (study II). This is paramount to make a coherent story and to enable a wider understanding and creating a sense of what happened (107). Medical as well as caring information and photos have to be complete in following the process, including all procedures and events. Missing dates or special events lead to distress and made it difficult to build memories. The ICU-diary helped the patient to build memories and reading the content helped to remember, amplified by the events described in the ICU-diary (study II). This is confirmed in a study by Storli and Lind (63) where patients describe that seeing a photo or reading about an event may help them remember a scent in the room or remember things connected with it. By including more details and photos in the ICU-diary the quality can be increased (63, 109, 110). The absence of evidence about the content and structure of the ICU-diary makes it difficult to create guidelines to improve the quality and makes the ICU-diary useful in the process to recovery.

"Help patients remember" include much more than just remembering. It is not only a question of simply to remember. The ICU-diary has to describe the critical illness and the time in ICU so that the patient can understand what happened and be able to connect this to feelings, experiences and physical rehabilitation. All information; medical, caring and daily activities have to be included in order to transmit the complete picture (study II). In study I there was a discrepancy between what was written in the ICU-diary and what was later related to the patient. By excluding certain information one reduces the patient's ability to obtain a complete picture of the ICU stay, which can affect the usefulness of the ICU-diary for the recovery (study I). Although the patients had been informed about the critical illness it was difficult to picture themselves as the person described in the ICU-diary. Photos appeared in about half of the ICU-diaries. There was a wide variance between having one or two random photos to more continuously occurring documentation picturing the critical illness progression, thus allowing it to be easily followed. Also the content in the photos varied due to the individual ICU routines (study I). This is confirmed in other studies where patients expressed that they wanted more photos (60, 62, 65). There were discrepancies about the staff opinion about

which photos to be taken and the photos' importance for the patients (study I) and the patients' opinion. Patients described that photos were not unpleasant to look at, it evoked different feelings and it was an important part of the ICU-diary. The patients wanted more photos to make it possible to follow the ICU stay and also photos from different kinds of events such as visitors, environment, medical and nursing interventions and procedures. The limited knowledge about the patient's perception of the photos leads to that the staff's perception determines which photos the ICU-diary contains and this is not always consistent with what the patients prefer. Searching for evidence can lead to EBC and the quality in the ICU-diary can be increased. Connecting the written content and photos gives a more complete picture which is important to make sense and enhance understanding (study II) which also is confirmed in other studies (29, 51, 109, 110). An ICU-diary with complete information helps the patient in a biological and psychological way to understand the physical impact of the critical illness and how this can affect the psychological. The ICU-diary can help the patient to make sense and cope with the experiences. But the results (study I, II) show that there have to be written guidelines for the content in the ICU-diary if it is to become a more useful tool for the patient. These guidelines have to be evidence-based to secure that the guidelines are grounded on research and clinical experiences. Using guidelines can reduce inappropriate variations practice and promote the delivery of quality care (111).

In study II the theme "Individualisation of care" includes the subtheme "a tool in rehabilitation". The ICU-diary can be a help in the patient's recovery process in different ways. The ICU-diary can be useful as a debriefing tool as the patient reads it over and over again. By recapitulating the ICU-diary content, the patients are able to reconstruct memories by confrontation with facts and events which help confirming scattered memories (study II). Jones et al. (112) found that what patient remembers from ICU changes over time. Memories described directly after ICU changes substantially from when described two months later. Not knowing what happened or if it was just a delusional memory was distressing for the patients. In this respect, the ICU-diary can be a help to sort and comprehend the memories. Patient described that reading about an event in the ICU-diary evoked a picture and a memory. The ICU-diary was also used as a memory information tool. When questions arose during the recovery process the answers and explanations could be found in the ICU-diary. If the

ICU-diary contains helpful information and photos, the patients can get a more realistic picture about the time and goals for recovery (study II). This is confirmed in other studies (60, 62, 63).
Sharing the traumatic event of the critical illness is an important part in the recovery process. The ICU-diary have an important role in this by explaining, informing and describing the ICU stay to the patient, giving an ability to understand what happened. Sharing the ICU-diary by reading it together with friends and relatives helps to start the communication and looking at the photos confirm what happened (study II). This is confirmed in a study of Engström et al. (62). Relatives helped the patients to remember by explaining and telling their story. Sometimes when the patient's memory or given information was not consistent with the relatives, the ICU-diary helped to clarify things (study II). The same result has been described by Combe (60).

All patients are not provided with an ICU-diary. This depended on different routines among the ICUs as the time in ICU before the start of the ICU-diary or if the patient was ventilator treated (study I). This was confirmed in study II where only half of the patients had an ICU-diary. Today there is no consensus when or who benefits the most from an ICU-diary. Usually, the ICU-diary was started after three days and even if there was a summary there was a risk that information from the most critically days was lost. Evidence-based guidelines for keeping ICU diaries can help to upgrade the ICU-diary to a potent tool to be used during recovery. The ICU-diary was mostly handed over to the patient when discharged from ICU (study I). Patients in study II said that the first time reading the ICU-diary was strongly emotional, evoked feelings and made them realise the closeness to death. This is confirmed in other studies (62, 110). Only six ICUs (study I) handed over the ICU-diary at the visit in the follow-up clinic. The majority left the ICU-diary with the patient at ICU discharge. Referring to the above mentioned experiences, there would probably be a need for the ICU nurse to go trough the ICU-diary with the patient in the ward. Today it has become more common with follow-up clinics for former ICU patients (31). This gives a possibility to hand over the ICU-diary when the patient visits the clinic and the nurse and the patient can go through the content and look at the photos together. To prevent the patients from being left with an ICU-diary which has evoked a lot of emotional feelings there have to be guidelines how the ICU-diary shall be handed over to the patient.

In the Scandinavian countries, Sweden, Denmark and Norway keep ICU-diaries. Different routines are used for keeping ICU-diaries in these countries. In Denmark guidelines for ICU-diaries have recently been published but follow-up clinics are not presently in common use. In Norway ICU-diaries have been a tradition for a long time (108) and national guidelines for keeping ICU-diaries have just been published (113). There is a need for evaluating the proceedings for keeping of ICU-diaries as it adds to the overall workload for the nurse (study I) and might as such discourage the initiation and daily keeping. The ICU-diary is a cheap intervention which can help the patient to reconstructing their memory from ICU and be a debriefing tool (59, 60, 109). However, there are limited studies about the content in the ICU-diary and how the ICU-diary is used. If keeping ICU-diary should be a useful and a high quality tool in the patients' recovery process there have to be evidence-based guidelines. To make it possible to give each patient an individual follow-up, the effect of follow-up clinics and the patient's needs have to be explored and evaluated.

Today existing guidelines usually describe the structure and not how to use photos or the content in the ICU-diary (6). The results of this thesis illuminate the necessity to meet the expressed needs and to fulfil the patients' wishes to give the ICU-diary its role as a powerful and useful tool in the patients' recovery. Simply confining to an arbitrary staff opinion on the content and use of the ICU-diary has been shown to be insufficient. The lack of evidence-based guidelines is problematic then the care is not based on research and knowledge but on local routines. Using evidence-based guidelines affects the nursing care and the patient outcome (114).

The recovery process can be a long and difficult process. To follow up the patients during this process and support them can give a better outcome. Today there are different routines for follow up depending on the hospitals. In the clinic there is also a lack of knowledge how the follow up program shall be planed for the patient (31). In a health care with limited financial and human resources the follow-up has to be customized based on the individual patient's needs. For this there have to be guidelines how a follow-up program shall be planned and which factors affecting when to follow up (54). These guidelines

have to be based on research and knowledge or colleagues and textbooks, i.e. evidence-based (114). There is existing research about the patients' problems after critical illness but knowledge about which patients, when and at what time the follow-up should be done are limit. Staffs at follow-up clinics have great experience about meeting patients during the recovery process but no evidence exist how a follow-up program shall be structured. The 3-set 4P questionnaire was developed to be used for identifying the patients individual needs for follow-up and to monitor the recovery process. To be a useful tool the instrument has to identify both physical, psychosocial problems and the follow up. Developing a new questionnaire is a difficult process where consideration must be given to methodological issues and psychometrically tests (98). The existing instruments validated for ICU patients are generic and not specific for measuring the individual patients' problems and need for follow-up.

In study III, the face and content validity of the questionnaire, 3-set 4P were tested with help of expert nurses and researchers and then applied on former ICU patients. The study verified that the patients understood the questions and the language used in the questionnaire (90). Former ICU patients can have cognitive problems and are usually tired after the illness, and therefore a questionnaire has to be simple and easy to respond. Due to this, and in light of the results in study III, the instructions and the questionnaire construction was simplified and made more uniform in order to be more user friendly (study IV). Free text response can give an opportunity to clarify if the questions are unclear and also indicate overlooked questions (98). However the alternative "free text responses" was excluded in study IV as few patients used this alternative.

To get knowledge about whether the developed questionnaire can be used to follow the patients recovery process over time it was mailed to patients who had been discharged from ICU 2, 6 or 12 months (study III). This can affect the results as the conditions can change during the recovery process. As this was a pilot study and further psychometrical tests have to be done the patients collected to study IV have two months discharge time from ICU. This can make the questionnaire generalizable. To optimize the response rate, the patients got a reminder (study III) and/or contacted by phone (study IV). The response rate in study III was good (80%) but in study IV it decreased (45%), probably due to larger sample. Comparing responder and non-responder showed differences between time in ICU and admission diagnosis (study IV). The inclusion time window (≥24 hours) can be a reason for this. This window

was chosen because of insufficient knowledge whether or not patients with short ICU time had post ICU problems. Maybe, these patients found the questionnaires too extensive and had difficulties to identify with the questions. Another reason for not answering the questionnaire explained in phone-contact was mental limitations that could have been present prior to the ICU period (study IV).

Construct validity and item reduction was based on exploratory factor analysis. Study III was a pilot study and the size of the sample was limited. In study IV where the questionnaire was further developed the sample size were sufficient. To emerge a stable factor structure there has to be a sufficient sample. In the literature there are discrepancies about a sufficient sample size to allow exploratory factor analysis, ranging from a minimum of 100 responders to five responders per item (98, 100). However, the factor analyses indicated acceptable explained variance in all three sets (study III, IV). Varimax rotation was used to maximize the factor structure (98) which resulted in minor differences between revealed factors in the pilot test (III) and in study IV. In the set "follow-up" more questions were included (study IV). This resulted in a four factor solution with more questions and a more suitable factor loading which decreased the risk for too high similarity between the questions in the factor (115). When developing a new questionnaire, concurrent validity has to be measured between the developed questionnaire and an established instrument, measuring the same phenomenon (99). SF-12 and SF-36 are both generic instruments and measures HRQOL. Although not quite equivalent concerning the studied phenomenon, these instruments were chosen and selected questions were used for performing concurrent validity between the established instruments and 3-set 4P. Correlation was moderate in most questions, depending on response alternatives and the time frame given in the questions. Nevertheless, if the correlation had been strong there would not have been a need for a new questionnaire.

Test-retest was used to measure stability-reliability. The time between test and retest can affect the result. When too short the patient remembers the answers from the previous session and if too long circumstances might have changed making the answers differ from the first time (99). As ICU patients usually are weak and can have concentration problems and both 3-set 4P and SF-36 are extensive questionnaires, one month between test and retest seems to be a

suitable time. In study IV, ICC was used instead of Spearman's correlation (study III) due to the fact that ICC is more reliable to measure correlation between two different response times. The fair correlation seen in questions in the set "physical" and set "psychosocial" can be explained by the change of these conditions mostly in the beginning of the recovery process indicating that the time between the first and second responses has to be shorter than one month to be representative. In study III there were three different groups of patients discharged from ICU two, six or twelve months before getting the 3-set 4P. The result in retest could have been affected due to that two of the groups (6 and 12 months) are past the first part in the recovery where the most changes occur.

The 3-set 4P is based on research and clinical experience and can be a basis when developing evidence-based guidelines for follow-up. The development of the 3-set 4P questionnaire has resulted in a questionnaire which can be refined to a more appropriate tool to monitor and evaluate the recovery of the ICU patient. The individual outcome of the use of the 3-set 4P can enhance the potential of the follow-up clinic as individual needs and pace of recovery can be identified and followed. Together with the patient, the nurse in the follow-up clinic can use the 3-set 4P to identify the patient's problems and how to support on an individual basis, evidence-based care.

Comprehensive understanding

Being critically ill is a traumatic event affecting the individual's life during and after the critical illness. The care for the patient continues after the ICU stay. Discharge from the ICU is a significant step in the process to recovery. To obtain recovery different tools are needed. Nursing care has a holistic approach where all the patients' needs have to be fulfilled. The patient sets the goals for the recovery and the staff support to achieve the goals. However, it is not always possible to regain the same status as before the critical illness. Instead, the goal for the recovery can be to live a satisfying life even with the limitations impaled by the illness.

Knowledge and understanding about what happened during the critical illness is essential to construct a personal coherent story and to achieve realistic expectations for the recovery goals. The ICU-diary has a holistic approach and can offer the patient an ability to make meaningfulness and comprehensibility of what happened. To make sense for the patient, the written content in the ICU-diary and the photos from the critical illness have to be in a chronological order, including and explaining the whole stay, not omitting any part of the story. The ICU-diary is essential, not only for providing information, but also to make sense and give a deeper understanding. In a biopsychosocial approach the ICU-diary can help the patients to understand how the critical illness affected the patients' physical and psychological well-being. Understanding the physical limitations and the speed of the progress can help the patients to set up realistic goals and decrease the psychological stress. The ICU-diary can also be used as a therapeutic treatment modality, to recapitulate and confirm the critical illness and as a part in communication. When feeling psychologically distressed, the ICU-diary can explain and help to make sense. This might help the patient to get further in the recovery process.

The goal for the recovery is personal and each patient has to set up and achieve his or her own goal. Obtaining health and well-being is essential and to support the patient the multiprofessional team has to identify which patients who have need for the support. An instrument to be used for this has to capture nuances in the individual patients' status, including physical, psychological and social

elements. A disease specific instrument, can detect which patient who has need for follow-up, when and how long. The developed 3-set 4P identifying physical, psychosocial problems and follow-up can be such an instrument. By identifying the individual patient's problems during the recovery process, the 3-set 4P provides an increased possibility to create an individual follow-up program. Follow-up clinics which occur in some hospitals can use the 3-set 4P as a tool for monitoring and evaluating patients' recovery in a more appropriate way.

Today, it is common knowledge that former critically ill patients have residual problems after the intensive care and that the patients need support during the process to recovery. Different tools can be used as a help in a follow-up. However, to secure that the available tools and the follow up have high quality, there is a need for developing evidence-based guidelines. A follow-up clinic which occurs in some hospital can be an essential part in the patients' recovery. These clinics are usually nurse-led. The 3-set 4P can be a useful tool for the nurse to get information about the patients' problems. This information can be used together with the ICU-diary to explain the critical illness and some of the residual problems. Maybe this also clarifies the connection between the patients' physical and psychosocial well-being. By discussing the critical illness the patient get an understanding and confirmation why they feel like they do. By aggregating evidence, clinical experience and the patient's perspective, the patient can set up goals for the recovery and the nurse identify the nature and amount of support to be given, i.e. EBC.

Conclusions

- Keeping ICU-diaries in ICUs in Sweden is common and the main purposes to keep ICU-diaries were to be a tool in the rehabilitation by helping the patient remember and give time back (study I).
- Recovery after critical illness can be difficult and different tools can be used to facilitate the process (study II).
- There are significant differences how to select patients to have an ICU-diary and structure of the ICU-diary. If the ICU-diary shall be a tool to construct a coherent story it has to include all information and photos in a chronological order. To fulfil the patients' wishes there have to be standards and guidelines for keeping ICU-diaries (study I, II).
- To get a coherent deeper understanding and meaning in the personal story and a realistic expectation of the recovery process different pieces have to be assembled in order to create a complete puzzle about the critical illness and stay in the ICU (study II).
- The 3-set 4P shows good construct validity and internal consistency and after some modification it can be used in clinical practice (study III, IV).
- The 3-set 4P can be used at the follow-up clinic to identify the individual patient's problems and create an individual program for recovery (study IV).
- Today there is no evidence about tools to use during follow-up. To promote high quality of the follow-up there is a need for guidelines. These guidelines have to be evidence-based.

Clinical and research implications

In the clinical practice with limited of time and resources, it becomes increasingly important to follow up the care of the former critically ill patient. Information on the individual patient's need gives an opportunity for customized rehabilitation. Different tools have to be used to help the critically ill patient during the process to recovery. The ICU-diary is a common used tool for the patient to build a comprehensive personal story about the time in ICU. In clinical practice, the staff keeps the ICU-diary to the critically ill patient. Today there are no guidelines for the keeping of ICU-diaries and to avoid random procedures and arbitrary staff opinions on the preferred content, guidelines has to be developed for the structure and content in the ICU-diary. The implication of such guidelines would better ensure that the ICU-diary can be a helping tool in the recovery process. The results of this thesis can be used when developing evidence-based guidelines (study I).

A part in the recovery process is to create an understanding and meaningful story about what happened, building a memory-puzzle. A follow-up visit where the ICU-diary is handed over to the patient is a part in the patients' recovery process. Revisiting the ICU can evoke hidden memories. Meeting the staff, get information and discuss what happened are other pieces in building the complete puzzle. The ICU-diary is only one piece in this process. Therefore, there is a need for further studies to investigate the importance of the ICU-diary and the circumstances of keeping and delivery. Studies to examine the ICU-diary as a psychological tool is warranted as the ICU-diary might serve the purpose of a cognitive behavioural therapy. The ICU-diary is a part in a personal story which has to be completed with other pieces likes a follow up visit and the important factor of a follow up visit and meeting the ICU staff (study II).

Today, in the clinical practice of ICU follow-up, there is sparse knowledge on which patients who have a need for follow-up or if there is a need to extend this over time. Using 3-set 4P in clinical practice can be a help in this process. Knowledge and information provided by the questionnaire might give a more complete picture that facilitates patient assessments and helps to allocate adequate resources during ICU promoting an evidence-based care. This is

important for the individual patient who needs support during the recovery but also from an economical and human resources perspective (study III, IV).

Further studies are needed to test 3-set 4P in different samples and in other cultures. 3-set 4P has to be tested over time to identify risk factors affecting the patients' physical and psychosocial health during the time in ICU. Studies about whether there are any factors or links that can identify patients with an increased need for extended follow-up and what resources they need for their recovery.

Summary in Swedish

”Till intensivvården kommer du för att leva, inte för att dö. Vi ger dig en chans att förlänga livet så att du kan ta tag i det igen och överleva – det är det vi jobbar med. Sen, när kroppen fått hjälp ska också själen få vård”. (Intensivvårdssjuksköterska Elisabeth Holmström, 2011)

Bakgrund

Patienter som kommer till en intensivvårdsavdelning (IVA), insjuknar oftast akut i ett kritiskt tillstånd med svikt i ett eller flera organ. Att vårdas på IVA innebär att vårdas i en högteknologisk miljö, där patienten är övervakad med medicinteknisk utrustning, ständigt omgiven av personal och med aktiviteter pågående dygnet runt. Miljön kan uppfattas obegriplig, skrämmande och stressande. Patienten har behov av övervakning och stöd av vitala funktioner med t.ex. ventilator och dialys. Detta medför att patienten har slangar kopplade till blodbanan för mätningar och infusioner samt ledningar för övervakning kopplade på kroppen. Patienten är omgiven av teknisk apparatur som ständigt låter. Den fysiologiska och mentala stressen reduceras genom tillförsel av sederande läkemedel. Tidigare var patienten djupt sederad men är idag sederad till komfortnivå vilket innebär att patienten är mer vaken och tidigt kan påbörja sin rehabilitering. De sederande läkemedlen och den kritiska sjukdomens påverkan på organen samt en rubbad sömncykel påverkar patientens minnen från IVA och kan ge amnesi, hallucinationer och overklighetsupplever. Den kritiska sjukdomen och att patienten är sederad förhindrar mobilisering vilket leder till muskelatrofi och muskelsvaghet. Dessutom kan den kritiska sjukdomen leda till att patienten blir katabol och malnutrierad.

De kritiskt sjuka patienterna är en heterogen grupp som lider av olika sjukdomar och har olika vårdtidslängd på IVA. Under vårdtiden på IVA utsätts patienten för många medicinska och vårdrelaterade interventioner som påverkar både patientens fysiska och psykosociala hälsa efter att de lämnat IVA. Vanligt förekommande fysiska problem är förlust av muskelmassa, muskelsvaghet, orörlighet, aptitlöshet, smärta, sömnstörningar mm. vilket påverkar patientens möjlighet till att leva ett normalt dagligt liv. Psykosociala problem efter intensivvård är vanliga och kan orsakas av att patienterna har få

tydliga minnesbilder från IVA. Istället har de minnen av overklighetsupplevelser beskrivna som upplevelser som är realistiska, detaljrika och verkliga för patienten men som inte förekommit. Patienter som har haft overklighetsupplevelser och inte har verkliga minnesbilder har en ökad risk att utveckla Posttraumatisk stressyndrom (PTSD). Andra problem är kognitiv dysfunktion i form av minnesproblem, koncentrationsproblem, mental förlångsamning mm. Konsekvenserna av detta blir en påverkan på patientens sociala liv och skapar ett beroende av hjälp från andra.
Återhämtningen efter vårdtiden på IVA skiljer sig mellan IVA-patienter och andra patienter då IVA-patienterna inte har klara minnen från vårdtiden och inte vet vad som hänt. Detta leder till att de inte vet varför de mår som de gör, vad de kan förvänta sig efter vårdtiden och inte kan sätta upp realistiska mål för återhämtningen. Patienterna har behov av att få information för att kunna skapa en personlig berättelse över vad som hände, en berättelse som hjälper dem vidare i återhämtningen.

Uppföljning efter IVA är en viktig del i patientens återhämtning och ansvaret för denna bör vara IVA-personalens. En del i uppföljningen är en dagbok med text och fotografier skriven under patientens vårdtid på IVA. Dagboken skall hjälpa patienten att fylla i minnesluckor, ge tid tillbaka genom att beskriva den medicinska vården, omvårdnaden och de dagliga aktiviteterna. Att läsa dagboken och se fotografier väcker olika känslor men även minnesbilder som ljud och dofter associerade med olika händelser. Dagboken kan vara ett hjälpmedel för patienten under återhämtningen och ge minskad risk för utveckling av PTSD. Idag saknas riktlinjer för innehållet i dagboken samt för användning av dagböcker. Det finns således ett behov av att utveckla riktlinjer för att säkra att dagbokens kvalitet och användbarhet som ett hjälpmedel under återhämtningen.

Uppföljning via en post-IVA mottagning kan vara en hjälp att tidigt upptäcka problem som patienten har. Under besöket får patienten information samt möjlighet att diskutera den kritiska sjukdomen, vårdtiden och rehabilitering till återhämtning. Idag finns ingen evidens och det saknas kunskap om vilka patienter som har behov av en sådan uppföljning, när i tiden den ska ske eller hur många besök som behövs. Olika instrument används för att mäta ”outcome” efter vårdtiden på IVA men det finns inget instrument anpassat till

IVA patienter. De instrument som finns är antingen domän-specifika och mäter en specifik domän t.ex. HADS som mäter ångest och depression eller också generiska som mäter hälsoprofiler t.ex. SF-36. Ett sjukdomsspecifikt instrument mäter patientens perception av en specifik sjukdom. Det är konstruerat för att identifiera klinisk relevant information och känsligt för att bedöma förändringar i hälsa relaterat till interventioner. Ett sådant instrument saknas i dagsläget för de patienter som varit kritiskt sjuka.

Återhämtning efter att ha varit kritiskt sjuk innebär oftast inte att patienten återhämtar sig till utgångsstatus. Patienter som varit kritiskt sjuka och nära att dö får en ny insikt i livet vilket påverkar deras uppskattning och tillfredsställelse med livet. Målet för återhämtningen är individuellt och det är patienten som sätter upp det. Processen till återhämtning är en aktiv process där patienten är ansvarig för att det individuella målet uppnås och det multidisciplinära teamet stödjer patienten i processen.

Syfte och resultat

Det övergripande syftet med denna avhandling var att beskriva och undersöka användningen av och innehållet i IVA-dagböcker och att utveckla och psykometriskt testa ett frågeformulär för att kunna upptäcka och följa IVA-patientens fysiska och psykosociala problem under processen till återhämtning.

Studie I syftade till att beskriva och jämföra omfattningen och tillämpningen av IVA-dagböcker på svenska intensivvårdsavdelningar i relation till olika IVA-kategorier (universitets-, läns- och länsdelssjukhus) och förekomst av post-IVA uppföljning. Telefonintervjuer utfördes utifrån en intervjuguide med personal på de 65 IVA i Sverige som använde IVA-dagbok. Materialet analyserades med beskrivande och jämförande statistik. En fråga, syftet med att skriva dagbok, analyserades med latent innehållsanalys. Resultatet visade att det vanligaste syftet med att skriva dagbok var att hjälpa patienten minnas och ge patienten tid tillbaka. Vilka patienter som fick dagbok, rutiner för fotografering, om det fanns ansvarig personal för dagboksrutiner, och uppföljning skiljde sig mellan de olika IVA-kategorierna. Dessa skillnader var inte baserade på evidens, pågående forskning eller utvärderingar utan berodde på den enskilda klinikens

rutiner. Det fanns en diskrepans mellan det uttalade målet med att skriva IVA-dagbok och de aktiviteter man utförde för att nå målet.

Den andra studien hade som syfte att undersöka vilket innehåll patienten föredrog att IVA-dagboken skulle ha samt hur patienten beskrev användbarheten. Ett frågeformulär besvarades av 115 patienter och 15 av dessa patienter djupintervjuades. Data analyserades i tre steg; frågeformuläret analyserades med beskrivande statistik, och kategorisering av innehållet medan intervjuerna analyserades med manifest innehållsanalys. Data från de olika analyserna kombinerades sen för att söka konvergens enligt mixed metod tradition. Resultatet visade att om patienten skulle kunna konstruera en sammanhängande berättelse var det viktigt att IVA-dagbokens innehåll var komplett med detaljerad information om dagliga aktiviteter, omvårdnad och medicinsk fakta och fotografier som kompletterade och gav en helhetsbild, allt i en kronologisk ordning. IVA-dagboken kunde då ge en förståelse och en känsla av sammanhang om vad som hade hänt. Dagboken användes också som hjälpmedel vid kommunikation med närstående och som informationskälla under återhämtningen.

Studie tre och fyra hade en metodologisk design med syfte att utveckla och psykometriskt testa ett frågeformulär det s.k.”3-set 4P” för att identifiera och bedöma fysiska och psykosociala problem samt uppföljning hos tidigare IVA-patienter under processen till återhämtning. Studie tre var en pilotstudie där frågeformuläret testades av 39 patienter. I studie fyra testade 421 patienter frågeformuläret efter att det modifierats utifrån resultatet i studie tre. Frågeformuläret konstruerades utifrån en litteraturgenomgång, klinisk kunskap och teoretiska erfarenheter som IVA-sjuksköterskor har från uppföljning av patienter efter IVA-vård. Frågeformuläret testades för innehålls-, teori- och jämbördig validitet samt stabilitets- och homogenitetsreliabilitet. Teorivaliditet av frågeformuläret genomfördes med en explorativ faktoranalys i varje separat del av 3-set 4P. Efter modifiering utifrån studie tre blev den bästa lösningen i studie fyra, en fyrfaktorlösning i den ”fysiska” delen, en femfaktorlösning i den ”psykosociala” delen och en fyrfaktorlösning i ”uppföljnings” delen. Jämbördig validitet mättes med ett urval av frågor i SF-12 (studie III) och SF-36 i studie IV. Resultatet var acceptabelt i båda studierna, då SF-12 och SF-36 är generiska instrument och frågorna inte var helt överensstämmande med 3-set 4P. Stabilitetsreliabiliteten utfördes med test-retest i båda studierna i studie III användes Spearman’s korrelationstest och i studie IV Intra-klass

korrelationstest (ICC). Resultatet i studie tre visade att ”uppföljnings” delen hade svag korrelation medan de två övriga hade acceptabel. I studie fyra hade den modifierade ”uppföljnings” delen stark till moderat korrelation medan den fysiska liksom den psykosociala delen hade svag till moderat korrelation. De frågor som hade svag korrelation i den fysiska delen var av samma karaktär i båda studierna. Detta skulle kunna bero på tidsintervallet mellan test och retest, då den fysiska funktionen förändras fortast i början av återhämtningen. Homogenitet mättes med Cronbach's alpha och var tillfredställande i båda studierna.

Övergripande förståelse

Att vara kritiskt sjuk är en traumatisk händelse som påverkar individens liv både under och efter den kritiska sjukdomsperioden. Vården fortsätter efter vårdtiden på IVA, men ett viktigt steg i återhämtningen är att lämna IVA. Kritiskt sjuka patienter som vårdats på IVA återfår sällan det status de hade före vårdtiden utan istället kan målet vara att leva ett tillfredsställande liv även om sjukdomen innebär begränsningar. Den enskilda patienten sätter upp målet för sin återhämtning och sjukvården stödjer patienten under processen att uppnå återhämtning. Under processen till återhämtning behövs olika ”verktyg” som hjälpmedel.

Kunskap och förståelse om vad som hände under den kritiska sjukdomen är viktigt för att bygga en personlig, sammanhängande berättelse och för att ha realistiska förväntningar på återhämtningen. En IVA-dagbok kan hjälpa patienten att ge mening och begriplighet i det som hände, men då måste IVA-dagbokens innehåll vara kronologiskt och inkludera samt förklara hela den kritiska sjukdomstiden utan att utelämna något. IVA-dagboken är viktig inte bara för att ge patienten information utan också för att ge en meningsfullhet liksom en djupare förståelse. Detta underlättar för patienten att förstå hur den kritiska sjukdomen påverkar det egna fysiska och psykosociala välbefinnandet. Förståelsen för de fysiska begränsningarna och dynamiken i förbättringen hjälper patienten att sätta upp realistiska mål för återhämtningen och minskar den psykiska stressen. Om patienten känner sig ledsen eller nedstämd används IVA-dagboken för att gå tillbaka och rekapitulera, förklara och bidra till att ge meningsfullhet vilket kan hjälpa patienten att komma vidare i återhämtningen.

Målet för återhämtning är personligt och varje patient måste själv sätta upp detta och arbeta för att uppnå sina mål. Att återfå hälsa och välbefinnande är viktigt och för att det multiprofessionella teamet skall kunna ge stöd måste de patienter kunna identifieras som har behov av stöd. Ett instrument att använda för identifiering av stödbehovet behöver fånga upp nyanser i den enskilda patientens fysiska och psykosociala status. Ett sjukdomsspecifikt instrument ska identifiera vilken patient som har behov av uppföljning, när detta behöver ske och hur länge patienten har behov av uppföljning. Det nyutvecklade 3-set 4P som identifierar fysiska och psykosociala problem samt uppföljning är ett sådant instrument. Post-IVA mottagningar kan använda 3-set 4P som ett verktyg för att skapa en individuell uppföljning för varje patient samt att följa och utvärdera den individuella patientens återhämtning på ett mer ändamålsenligt sätt.

Idag finns det kunskap om att tidigare kritiskt sjuka patienter har kvarstående problem efter vårdtiden på IVA och att de har behov av stöd under återhämtningen. Olika verktyg används som hjälp under uppföljningen, men för att säkerställa att de tillgängliga verktygen och uppföljningen har hög kvalitet finns det ett behov av att utveckla evidensbaserade riktlinjer. En post-IVA mottagning oftast sjuksköterskeledd är en viktig del i uppföljningen. Om 3-set 4P används ger informationen från 3-set 4P tillsammans med IVA-dagboken förklaring av den kritiska sjukdomen och de kvarstående problemen. Patienten och sjuksköterskan diskuterar den kritiska sjukdomen och patienten kan få en förståelse och bekräftelse i varför de mår som de gör. Aggregation av evidens, klinisk erfarenhet och patientens perspektiv, hjälper patienten att sätta upp mål för återhämtningen och sjuksköterskan att identifiera vilket och hur mycket stöd som skall ges, d.v.s. EBC.

Slutsatser

- användning av IVA-dagböcker var vanligt förekommande på IVA i Sverige. Syftet med att använda IVA-dagbok beskrevs som ett verktyg i rehabiliteringen genom att hjälpa patienten att komma ihåg och ge tid tillbaka (studie I)
- återhämtning efter kritisk sjukdom är komplicerat och olika verktyg behöver användas för att underlätta processen (studie II)

- det finns betydande skillnader i vilka patienter som valdes ut att få en dagbok samt i strukturen i IVA-dagboken. Om IVA-dagboken skall vara ett verktyg för att konstruera en sammanhängande berättelse måste den innehålla all information samt fotografier i kronologisk ordning. För att uppfylla patientens önskemål måste det finnas riktlinjer för IVA-dagboken (studie I, II)
- för att få en sammanhängande och djupare förståelse och mening i den personliga berättelsen och en realistisk förväntan på återhämtningen måste olika delar sättas ihop för att bilda ett komplett pussel över den kritiska sjukdomen och vårdtiden på IVA (studie II)
- 3-set 4P visade bra teorivaliditet och stabilitetsreliabilitet och är efter viss modifiering användbart i klinisk praxis (studie III, IV)
- 3-set 4P kan användas på post-IVA mottagningar för att identifiera enskilda patienters problem och skapa ett individuellt program för återhämtning (studie IV)
- idag finns det ingen evidens för vilka verktyg som skall användas under uppföljningen efter intensivvård. För att främja hög kvalitet på uppföljningen finns det behov av riktlinjer. Dessa riktlinjer måste vara evidensbaserade.

Kliniska och forskningsimplikationer

I den kliniska verkligheten med begränsade resurser är det viktigt att följa upp de patienter som vårdas på IVA. Information om den individuella patientens behov ger en möjlighet för individuellt anpassad rehabilitering. Olika hjälpmedel kan användas under återhämtningsprocessen. IVA-dagboken är ett hjälpmedel som har olika funktioner. Idag saknas gemensamma riktlinjer för struktur och innehåll i IVA-dagboken. För att förhindra att ett slumpmässigt förfarande och godtyckliga åsikter avgör innehållet i IVA-dagboken måste riktlinjer utvecklas. Implementering av riktlinjer kan säkra att IVA-dagboken kan vara ett användbart hjälpmedel under återhämtningen. Resultatet i denna avhandling kan användas vid utveckling av riktlinjer baserade på evidens.

Ett uppföljande besök på IVA och att få IVA-dagboken är en del i återhämtningsprocessen. Patienten skapar en individuell berättelse som ger begriplighet och förståelse i vad som hände. Återbesök på IVA väcker ”gömda” minnen, att träffa personalen, få information och möjlighet att diskutera och

ställa frågor är en annan viktig del. IVA-dagboken är endast en del och det finns behov av studier som undersöker vilka delar som behövs för att patienten skall kunna bygga en berättelse som understödjer processen till återhämtning. IVA-dagbokens funktion i återhämtningen som ett psykologiskt verktyg behöver undersökas.

Idag saknas kunskap om vilka patienter som är i behov av uppföljning, när denna ska ske och hur uppföljningen av patienten ska struktureras. 3-set 4P kan ge kunskap och information som kompletterar bilden av patientens behov och stöd samt hjälper till att anslå resurser för att möjliggöra en evidensbaserad vård. Detta är viktigt för den individuella patienten, men även ur ett mänskligt och ekonomiskt perspektiv.

3-set 4P behöver testas ytterligare i andra och större urval av patienter och i olika kulturer samt över tid för att identifiera om det finns faktorer på IVA eller andra faktorer som påverkar patientens fysiska och psykosociala återhämtning. Ytterligare kunskap behövs om det finns individuella faktorer som kan identifiera patienter som har ett ökat behov av uppföljning.

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Questionnaire to patients after ICU stay

Respond by filling in the dotted line or mark with an X in the box at your answer. If you check the box "other" fill in the dotted line with what concerns you.

Background Questions

1. Enter your gender Man ☐ Woman ☐

2. What year were you born 19……

3. What is your current employment?

Occupational employment ☐
Student ☐
Unemployed ☐
Retired ☐
Other ☐

.....

4. Have you returned to the work you had before the time at ICU? Yes ☐ No ☐
If No, are you in the sick list
Full-time ☐
75% ☐
Half-time ☐
Other ☐

.....

5. What education do you have?

Primary school ☐
Secondary school ☐
University ☐
Other education ☐

.....

6. What is your marital status?

Single ☐
Partner / married ☐
Other ☐

.....

7. How many months since you left ICU? .....……..months

8. How would you say that your general health was before the time at ICU?

- Very bad ☐
- Poor ☐
- Fine ☐
- Very Good ☐
- Excellent ☐

9. Before ICU stay, my physical health was

- Very Good ☐
- Pretty Good ☐
- Neither good nor bad ☐
- Pretty bad ☐
- Very bad ☐

10. Before ICU stay, my psychosocial health was

- Very Good ☐
- Pretty Good ☐
- Neither good nor bad ☐
- Pretty bad ☐
- Very bad ☐

11. During ICU stay, I had hallucinations

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐

12. During ICU stay, I had unreality experiences

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐

13. During ICU stay, I had nightmares

- Very much agree ☐
- Much agree ☐
- Partly Agree ☐
- Disagree ☐

My Physical health today

Questions answered by X in the box that best applies to your physical health **TODAY**.
When you answer the questions below, **base your answers on how it's been the last week.**
Answer option **NOT current means** that the issue can not be answered as you **had these problems before your ICU stay**

1. My physical health last week has been

- Very Good ☐
- Pretty Good ☐
- Neither Good nor bad ☐
- Pretty bad ☐
- Very bad ☐

2. After ICU stay, the movement of my muscles and/or joints has become

- Much better ☐
- Slightly better ☐
- No change ☐
- Slightly worse ☐
- Much worse ☐

3. After ICU stay, my physical condition has become

- Much better ☐
- Slightly better ☐
- No change ☐
- Slightly worse ☐
- Much worse ☐

4. I am now limited in my daily activities due to my physical health at moderately strenuous activities such as walking

Yes ☐ No ☐ Not current ☐

5. I am now limited in my daily activities due to my physical health when I climb several steps

Yes ☐ No ☐ Not current ☐

6. I have pain or ache that affects my daily work
(work involves both at home and at work) Yes ☐ No ☐ Not current ☐

7. After ICU stay, my appearance has changed

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐

8. After ICU stay, I have lost much hair

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

9. After ICU, my skin has changed (for example, pigment changes)

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

10. After ICU, my appetite has decreased

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

11. After ICU, I have swallowing problems

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

12. After ICU, I have regained the weight I had before ICU

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

13. After ICU, my muscles have become smaller/weaker

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

14. After ICU, I have had problems with stomach / intestinal function (such as diarrhoea)

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

My Psychosocial health today

Questions answered by X in the box that best applies to your psychosocial health **TODAY**. When you answer the questions below, **base your answers on how it's been the last week.** Answer option **NOT current means** that the issue can not be answered as you **had these problems before your ICU stay.**

1. My mental health last week has been

- Very Good ☐
- Pretty Good ☐
- Neither Good nor bad ☐
- Pretty bad ☐
- Very bad ☐

2. After ICU, I have problems to fall asleep

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

3. After ICU, I have problems with regular nightmares

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

4. After ICU, I have problems going back to sleep, in case I wake up at night

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

5. After ICU, my short-term memory has impaired

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

6. After ICU, I have problems remembering the names of people I know

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

7. After ICU, I do not remember events that happened before ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

8. After ICU, I find it hard to concentrate when I read the newspaper

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

9. After ICU, I find it difficult to read books because I do not remember what I have read

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

10. After ICU, I have become more sentimental

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

11. After ICU, I have anxiety attacks

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

12. After ICU, I become more easily angry or irritated

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

13. After ICU, I have been depressed

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

14. After ICU, I have become more peaceful and harmonic

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

15. After ICU, my social life has impaired

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

16. After ICU, I have an increased need to be alone

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

17. After ICU, I have avoided people who recall me of my ICU stay

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

18. After ICU, I have avoided places with a lot of people such as stores

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

19. After ICU, my social relationships have been enhanced

Very much agree ☐
Much agree ☐
Partly agree ☐
Disagree ☐
Not current ☐

20. After ICU, I still suffer from unreality experiences

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

21. After ICU, I have been able to talk about the unreality experiences

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

Follow-up after ICU stay

A question answered by an X in the box is your answer. Answer option **NOT current means** that the issue can not be answered as you have not received information or had follow-up.

1. I have been properly informed of the medical reason for my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

2. I have been properly informed about my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

3. I have today a need to talk about my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

4. I am satisfied with the physical follow-up after my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

5. I am satisfied with the mental follow-up after my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

6. I am pleased with the help I received with the physical problems I had after my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

7. I am pleased with the help I received with the mental problems I had after my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

ICU-Diary

Following questions shall be answered **if you have had** a diary over the ICU stay. If you **NOT** received a diary mark with an X in the box "**NOT CURRENT**"

1. It has been positive to have a diary over my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

2. The diary has been valuable for me during my rehabilitation

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

3. The diary has given me a deeper understanding of what happened to me during my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

4. The diary has helped me fill in memory gaps from my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

5. The diary has been used as a basis for talks with others about my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

6. The diary has created new questions about what happened to me during my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

Follow-up visit to ICU

Following questions shall be answered **if you have had** a follow-up visit to ICU after your ICU stay. If you **NOT** have had a follow-up visit mark with an X in the box "**NOT CURRENT**"

1. On the follow-up visit, I have been properly informed about the medical reason for my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

2. On the follow-up visit, I have received satisfactory information about my ICU stay

- Very much agree ☐
- Much agree ☐
- Partly agree ☐
- Disagree ☐
- Not current ☐

3. The follow-up visit to the ICU was positive

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

4. The follow-up visit to the ICU has been useful for me in my continuing rehabilitation

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

5. The follow-up visit has helped me in the processing of my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

6. Information on the follow-up visit has given me a deeper understanding of the problems I can have after my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current

7. After the follow-up visit, I can talk more easily about the experiences I had during my ICU stay

- ☐ Very much agree
- ☐ Much agree
- ☐ Partly agree
- ☐ Disagree
- ☐ Not current